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DEPARTMENTS OF LABOR, HEALTH AND HUMAN SERVICES, EDUCATION AND RELATED AGENCIES APPROPRIATIONS FOR FISCAL YEAR 1991

HEARINGS

BEFORE A

SUBCOMMITTEE OF THE

COMMITTEE ON APPROPRIATIONS

UNITED STATES SENATE

ONE HUNDRED FIRST CONGRESS

SECOND SESSION

ON

H.R. 5257

AN ACT MAKING APPROPRIATIONS FOR THE DEPARTMENTS OF LABOR, HEALTH AND HUMAN SERVICES, AND EDUCATION, AND RELATED AGENCIES, FOR THE FISCAL YEAR ENDING SEPTEMBER 30, 1991, AND FOR OTHER PURPOSES

Part 3 (Pages 1-786)

Nondepartmental witnesses

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DEPARTMENTS OF LABOR, HEALTH AND HUMAN SERVICES, AND EDUCATION AND RELATED AGENCIES APPROPRIATIONS FOR FISCAL YEAR 1991

TUESDAY, MARCH 20, 1990

U.S. SENATE,
SUBCOMMITTEE OF THE COMMITTEE ON APPROPRIATIONS,
Washington, DC.

The subcommittee met at 9:36 a.m., in room SD-138, Dirksen Senate Office Building, Hon. Tom Harkin (chairman) presiding.

Present: Senators Harkin and Burdick.

NONDEPARTMENTAL WITNESSES

Senator HARKIN. Good morning, the subcommittee will come to order. This morning we begin the first of 6 days of public witness testimony focusing on programs funded by the Subcommittee on Labor, Health and Human Services, Education and Related Agencies.

During these several sessions, the subcommittee will hear testimony from approximately 150 witnesses. It is a matter of regret to all of the members of this subcommittee that we have had to limit the number of witnesses that we are able to hear this year. But you have all been very understanding about our time constraints, and I do want to assure you that witnesses who have their testimony to the subcommittee staff by April 9 will have that testimony put into the hearing record.

In order to help us stay on schedule, we are going to use the red light, green light system, I guess. Based on a letter that you received from me, each witness has 3 minutes in which to present his or her oral testimony. When the red light goes on, your 3 minutes have expired.

Again, I will amend that a little bit, of course, but again, I just want to ask to be as succinct as possible, to keep in mind what are the one or two or three things that you really want to have me know, and the staff here know that you want to highlight out of the testimony. And I would appreciate it, again, if you would do that and keep in mind—be considerate of the other witnesses who also are here, and the time constraints under which we do operate.

So, I would like to welcome you all to the committee.

STATEMENT OF SHERRY TOWNSEND BOLT, PAST PRESIDENT, PLANNED PARENTHOOD OF MID-IOWA, ON BEHALF OF PLANNED PARENTHOOD FEDERATION OF AMERICA

Senator HARKIN. Because of travel constraints and the weather being what it is, we have some people here who must catch transportation back out of Washington. So I am going to open the hearing and go a little bit out of order, and I am going to start first with Sherry Townsend Bolt, past president of Planned Parenthood in Mid-Iowa and the Planned Parenthood Federation of America, Inc. Again, Sherry, welcome to the subcommittee.

Ms. BOLT. Thank you very much.

Senator HARKIN. I appreciate your being here. We do have a copy of your testimony, and it will be made a part of the record in its entirety. You will be testifying, I guess, about title X, family planning. In fiscal year 1990, we had $139.1 million which we had appropriated.

For 1991, the request is for the same amount, $139.1 million, which is basically a cut, and so, that is what we have in front of us, and again, welcome. I am glad you are here, and please proceed as you so desire.

Ms. BOLT. Thank you very much, Chairman Harkin and members of the subcommittee. My name is Sherry Townsend Bolt. I am immediate past chair of the Board of Directors of Planned Parenthood of Mid-Iowa. I am today submitting testimony on behalf of Planned Parenthood Federation of America in place of its president, Faye Wattleton, who was unable to be here.

It is an honor to testify before this subcommittee in support of title X, and particularly before you, Chairman Harkin. As I have traveled around Iowa during the past 2 years, it has been very evident that the citizens of our State are aware of your efforts and very grateful to you for your commitment and hard work on behalf of the Nation's family planning program.

Since 1970, title X has served as the mainstay of our national family planning effort. Each year, 4,500 local clinics around the country provide medical and educational services to over 5 million low-income women and teenagers. While the primary focus of title X is contraceptive services, title X-supported clinics offer basic, preventative health services, and are often the first place where low-income women and especially teenagers, receive formal medical care.

Title X is a program that works. It provides needed health care services. It prevents unintended pregnancies and the need for abortion. It effectively addresses teen pregnancies. And Mr. Chairman, title X is cost effective.

A recent study by the Alan Guttmacher Institute found that every public dollar spent to provide contraceptive services, saves an average of $4.40 in taxpayer funds that otherwise would have to be allocated toward medical care, welfare, and other mandated social services, an overall total of $1.8 billion in savings annually.

Our State of Iowa illustrates the need and value of federally supported family planning program. In 1987, Iowa had 155,690 teenage and poor women at risk for unintended pregnancy. In a recent 4-year period, the number of births in Iowa to unmarried women grew from one out of every eight to one out of every 5.7.

A 1985 report by the University of Iowa's Center for Health Services found that for from the age group 4 through 19, every dollar spent on family planning saved the State $8.50 in unspent welfare support each year. Yet, despite this need for family planning services and despite the accomplishments and proven costs savings of the title X program, title X funds for Iowa have been cut 17 percent over the course of the last decade.

Nationally, the program funding has declined from $162 million in 1981 to less than $140 million today.

The critical complement to family planning services for preventing unintended pregnancies, and thus reducing the need for abortion, is improved contraception. The inadequacy of available contraceptive methods in this country is reflected in the fact that more than one-half of the nearly 6 million pregnancies that occur each year in the United States are unintended.

Mr. Chairman, we commend you for your leadership in this area. Your recently introduced bill to establish contraceptive and infertility research centers will lead to the development of safer, more effective methods of contraception.

Federally funded family planning clinics are logical sites for the testing and treatment of sexually transmitted diseases. Former U.S. Surgeon General, C. Everett Koop and other public health officials have recommended that family planning clinics help provide AIDS testing and counseling services, especially to HIV-positive women who may become pregnant.

But if family planning clinics are to be able to address these additional needs, additional funds are required.

Last year, you included in your appropriations bill, a pediatric AIDS initiative which targeted an additional $10 million to family planning clinics for HIV counseling, testing, and outreach. This provision was dropped in conference. We ask that you reinstate it in this year's legislation.

Title X has taken some hard hits over the last decade. The need for services has increased and funding has been cut. In addition, the Reagan administration issued the gag rule. These regulations forbid doctors and other medical professionals from giving their patients objective information or referrals regarding their legal options when facing an unwanted pregnancy.

For the moment, these guidelines are enjoined by the courts. These regulations are opposed by 36 State governments, 78 national organizations, including every major medical association, and the deans of each of the United States' 25 schools of public health.

We ask that you reject these regulations in the committee report on the Labor-HHS appropriations legislation. Congress has spoken before on this issue. By reinstating your intent, you will be protecting the privacy rights of women and the ethical responsibility of medical professionals to their clients.

PREPARED STATEMENT

It is vital that title X funding be increased. Continuing efforts must be made to bring spending for family planning to levels that will ensure the continuation of services now being provided and to reach the millions of women and teenagers in need of our services.

I thank the Chair and the subcommittee for this opportunity to testify.

[The statement follows:]

STATEMENT OF PLANNED PARENTHOOD FEDERATION OF AMERICA

I am Faye Wattleton, President of Planned Parenthood Federation of America (PPFA). I am appearing today on behalf of the more than 30,000 volunteers and staff who operate our 172 affiliates in 46 states and the District of Columbia, the 300,000 individuals who contribute to our organizations, and above all, the more than 4 million women and men who are served by our clinics each year. I want to thank you and this subcommittee for the opportunity to present our views on the need to strengthen the national family planning program and to expand research in contraceptive technology.

Family Planning Services

Title X of the Public Health Service Act is the core of our national family planning clinic network that provides subsidized services to some 4 million low-income women and teenagers. Title X remains the only program through which Congress can affect and monitor the reach of family planning services; it provides half of all federal funds for basic services; it serves as the base from which other sources of support -- state and local -- can be derived. From its earliest days, Title X has enjoyed bipartisan support in both houses from members of Congress who embrace the concept of voluntary family planning as a tool to enhance the health and welfare of mothers and children -- and to reduce the need for abortion -- through the prevention of unintended pregnancy.

The plan to reorganize the Public Health Service, which would remove the locus of control of its component programs from the regional offices to the various HHS central offices in Washington, is unnecessary. This effort is being suggested as a way to more effectively manage programs under the auspices of the Public Health Service. Title X has been well managed at the regional level since its inception in 1970. We see no need to alter the system at this time. Please repeat the directive included in the FY 1990 Labor-HHS-Education Conference Report not to reorganize the Public Health Services regional offices.

The Title X program provides basic preventive health services to a large group of medically underserved women. In addition to providing contraceptive services (including natural family planning) and infertility diagnosis, Title X-supported clinics also offer health screening assessments and either simple treatments or referral for anemia, hypertension, cervical and breast cancer, sexually transmitted diseases, kidney dysfunction and diabetes. Clinics such as those financed through Title X often are the initial entry point for low-income women - and especially teenagers - into the health care system.

Yet, despite the accomplishments of the Title X program, a tremendous number of women continue to go unserved. We know that as of 1987, there were approximately 31.8 million low-income women at risk of unintended pregnancy in the United States (that is, sexually active, fertile and not seeking to become pregnant). However, there is a serious, continuing deficiency at DHHS in collecting and analyzing national program data. Information has not been collected or analyzed regarding the numbers of women needing services since 1983, despite repeated promises by the Department that it would do so. Thus, while we know, for example, that 31.8 million women nationwide are at risk of unintended pregnancy, we have no up-to-date information on how many of these women are being served in federally-funded family planning clinics, or even how many clinics are now in operation. During a time of careful attention to government spending, it is critical to have this information both for congressional oversight and in order for DHHS to allocate funds where they will be most efficiently spent. However, we know that, as of 1983, the organized clinic system made family planning services available to almost 5 million women, 1.6 million of whom were teenagers and 80 percent of whom were low-income, i.e., below 150 percent of the poverty line. Title X continues to be a major source of funds for this network, comprising 34 percent of the total federal and state expenditures.

The growing need for the contraceptive and basic reproductive health services provided by Title X has been met by a shrinking federal commitment of funds. In FY 1981, Title X was funded at $162 million. The effects of the 25 percent cut later that year and in FY 1982 were severe. Straining to avoid turning patients away, clinics around the country were forced to reduce the scope of their services, especially community outreach to "hard to serve" patients. They have found it difficult to maintain, much less expand, educational programs geared toward adolescents and their parents -- exactly the sorts of programs Congress wants from Title X. A $16 million increase in FY 1894 and an additional $2.5 million for FY 1985 brought Title X funding from $124 million in FY 1982 to $142.5 million in FY 1985. Funding remained frozen at that level for the next two years, and has dropped even further since that time, to below $140 million. Furthermore, two years ago, the transfer of administrative expenses from a general PHS account to the Title X account resulted in a $6 million dollar cut in services.

We urge the Congress and this committee to continue and increase its important investment in the Title X program -- one federal program where a relatively small increase in spending this year results in tremendous savings in health care and social services costs to the government for many years to come. I would like to draw your attention to a new study just released by the Alan Guttmacher Institute (AGI) assessing the value of the preventive health services offered by publicly funded family planning providers, a copy of which is attached. Understandably, at a time when your committee is paying particular attention to programs which are not only beneficial to people's health, but cost effective as well, such a study becomes an important evaluative tool.

According to the AGI study, almost one in four women in the United States who uses a contraceptive method (other than sterilization) obtains it from a publicly subsidized source. Over 90 percent of these women -- 4.1 million -- rely on family planning clinics; the rest, about 400,000 depend on private physicians who are reimbursed by Medicaid. Because neither contraceptives nor the women who use them are perfect, these 4.5 million women experience approximately 430,000 unintended pregnancies a year. What the new AGI calculations show is that, in the absence of government support for family planning services, an average of 1.2 million additional unintended pregnancies could be expected to occur each year among these women, at least four in 10 of which would end in abortion. The new AGI study shows that every public dollar spent to provide contraceptive services saves an average of $4.40 in taxpayer funds that otherwise would have to be allocated towards medical care, welfare and other mandated social services -- an overall total of $1.8 billion in savings annually. Moreover, there are critical individual and social costs which the teen pregnancy program preempts as well; in the absence of publicly funded services, 509,000 additional unintended births and 516,000 additional abortions would occur each year in the United States.

Two Title X reauthorization bills are currently pending before Congress, H.R.930 and S.110. The House bill sets an authorization ceiling of $164.2 million for fiscal year 1991 and the Senate measure calls for $171 million, both representing an increase over last year's appropriation, but still far closer to the funding level for fiscal year 1981 than to the appropriate level for 1991. Given the current budget deficit, we realize that the restoration of funding adequate to meet the need that exists cannot happen overnight. However, it is vital that Title X be funded at the full amount authorized by law. Continuing efforts must be made to bring Title X to funding levels that will ensure the continuation of services now being provided -- and to make progress towards expanding services to the millions of women and teenagers in need who are presently not being served. Clearly, as the AGI study demonstrates, federal investment in less expensive preventive services now will avoid the need for larger outlays for more costly services later.

STDs & HIV Testing and Counseling

There is no doubt that federally funded family planning clinics would also be the logical sites for other types of related health care, beyond the wide range of services they already offer. As we have known for years, Title X-supported clinics are often the only source of reproductive health care for a low-income woman or teenager. Certain types of sexually transmitted diseases, such as chlamydia and the human papilloma virus, which can lead to infertility and cervical cancer respectively, could be treated before becoming disabling or deadly if every family planning clinic could afford to offer such services.

In addition, former U.S. Surgeon General C. Everett Koop and other public health officials have recommended that family planning clinics help provide AIDS testing and counseling services, especially to HIV-positive women who may become pregnant. Nonetheless, if family planning clinics are to be able to address these additional needs, it is obvious that additional funds for this purpose are required. Last year, the Senate appropriations bill contained a "pediatric AIDS initiative," which specifically targeted an additional $10 million to family planning clinics for HIV counseling and testing. Although that effort was unsuccessful, we request that the extra $10 million in new funds be reinstated in this year's legislation, and that it be directed to the existing network of family planning clinics around the country.

The "Gag Rule"

Looking beyond the statistics and the proven record of accomplishment of Title X-supported programs, I believe the time has come to question the motives and the illogical proposals of those who, explicitly or not, seek to destroy the current national family planning effort. These attacks, and calls to curtail or eliminate the delivery of family planning services, come almost exclusively from organizations whose primary stated mission is to criminalize abortion. Is it possible that they don't realize that eliminating the Title X program would lead to an increase in abortions? That deterring teenagers from seeking contraceptives by imposing parental consent or notification requirements would lead to still more pregnancies among teenagers and more abortions? That excluding medically responsible individuals and organizations from the Title X program or from contracting for delivery of family planning services at home or overseas will lead only to more abortions?

We commend the members of this committee and you, Mr. Chairman, for having resisted riders that would have prohibited family planning clinic personnel from giving their patients confronting an unintended pregnancy full information about their legal medical options. Nevertheless, contrary to congressional intent, in 1988 the Reagan administration issued regulations barring Title X-funded clinics from providing any women who so request it information, counseling, or referrals regarding their options when facing an unintended pregnancy. These regulations were opposed in comments filed by 36 state governments, 78 national organizations (including every major medical association) and the deans of all 25 schools of public health in the country, and have been enjoined by two federal district courts.

Congress has spoken on this matter before. However, we ask that you speak once again, this time in the committee report on the Labor-HHS appropriations legislation you are now preparing to consider. By reiterating congressional intent, you protect each woman who seeks information through a Title X funded clinic, ensuring that she receives the same medical information that someone who can afford a private physician receives.

Teenage Pregnancy

While divisions on the question of abortion may persist, I submit to you that we must all work together in supporting the means to reduce the need for abortion. Title X is the most tangible vehicle the federal government has for approaching that goal, both for low-income women and teenagers, although another program often linked politically with the Title X legislation, the Adolescent Family Life program (AFLA), was set up as a series of demonstration projects to test the efficacy of telling teenagers to "just say no." Since fiscal year 1987, appropriations for this program have fallen from 14.5 million to 9.5 million last year. We understand the committee's reluctance to fund this program and note that the Senate is currently considering a much more realistic and better conceived program to address the problems and needs of teenagers seeking to avoid pregnancy, as well as pregnant and parenting teens. Should this measure, S.120, become law, we hope that the committee will give careful consideration to its funding needs.

Contraceptive Research and Development

Similarly, we urge you to give careful consideration to increased support for population research, specifically authorized under Title X and Section 301 of the Public Health Service Act, and to place particular emphasis on applied research leading to the development of new and better birth control products, and on research designed to evaluate the safety and efficacy of existing methods. The inadequacy of available contraceptive methods is reflected in the fact that more than half of the approximately six million pregnancies that occur each year in the United States are unintended. Moreover, women in the United States are limited in their contraceptive options compared to women and couples in other countries.

Of 36 million American women who are seeking to avoid pregnancy, three million are using no contraception, and another three million are using the least effective methods. A study published last summer by The Alan Guttmacher Institute showed that, even among those women using the more effective methods, contraceptive failure rates were much higher than generally thought. The most common reason cited for using no method is the fear of possible side effects, despite an increasing body of research proving the safety and efficacy of several major methods. It is critical that further studies be pursued to identify and counteract the specific risk factors that do exist. At the same time, intensified research in the development of new and improved methods of contraception could greatly enhance our ability as a society to lower the staggering 55 percent incidence of unintended pregnancy that still exists in this country today.

We understand that the Food and Drug Administration has before it a unanimous recommendation from its Fertility and Maternal Health Drugs Advisory Committee and may soon give its formal approval for the use of Norplant -- a subdermal contraceptive implant -- in this country. Yet there are nearly 100 new varieties of contraceptives at various points in the R&D process around the world, including several at NICHD. Some companies even have products ready for field trials, but cannot get the insurance so that testing may proceed. With half of the pregnancies in this country unintended, the narrowing of effective choices of contraception constitutes a national tragedy.

There will probably never be a single perfect contraceptive, since individual circumstances change over a lifetime, as do family planning goals and attitudes. Yet in spite of the universal interest in better contraception, federal support for development of new or improved methods, as well as for the evaluation of the safety and effectiveness of current ones, has actually declined since FY 1981. A recently published report by the National Research Council and the Institute of Medicine, Developing New Contraceptives: Obstacles and Opportunitites, revealed a range of obstacles currently facing contraceptive research, development and marketing in this country. Prominent among them are insufficient and unstable funding, which has declined worldwide by about 25 percent in real dollars since the mid-1970s; the high cost of liability insurance for contraceptive products, which together with the virtual impossiblity of obtaining insurance for clinical tests on humans, is leading to a near-paralysis of research into new methods; and the complex premarketing requirements and regulatory procedures of the FDA which delay approval of many methods for use in the United States. Not surprisingly, only one private pharmaceutical company in this country remains in the business of conducting contraceptive research and development directed towards the United States market. These obstacles may be daunting, but hopefully they are not insurmountable. Among other recommendations, the NRC/IOM report suggested that since there has been "a flagging commitment to contraceptive development in the United States," that the federal government "should increase funding and adopt arrangements that provide long-term stability for priority research projects."

Title X currently authorizes biomedical research in the reproductive sciences, social and behavioral studies, contraceptive development and contraceptive evaluation. The National Institute of Child Health and Human Development (NICHD) administers all these areas of research, which together are presently funded at approximately $128 million (only a tiny fraction of the total NIH budget) and with only $8 million specifically targeted to contraceptive development. Perhaps part of the reason this area of study receives such a low priority at the National Institutes of Health (NIH) is that NIH is primarily disease-oriented, whereas research of this type mainly benefits healthy people. The irony, of course, is that the strides we are able to make as a society in this field directly touch the lives of virtually all Americans, not to mention the rest of the world, for which NIH is the major source of research in contraceptive technology and development.

As you have recently heard from administration testimony, NICHD continues to state that its Contraceptive Development Initiative is a priority. However, prior funding commitments may make that initiative less a reality than planned. Mr. Chairman, we need new methods of contraception. And we need to reassure ourselves about the safety and efficacy of current ones. We applaud NICHD's efforts in this area. At the same time, we strongly urge you to endorse a specific increase of $10 million for applied research in contraceptive development and evaluation, either through an earmark or committee report directives.

Recommendations

In conclusion, Mr. Chairman, Planned Parenthood respectfully makes the following recommendations to the subcommittee:

- First, that the Title X family planning program be funded at the full amount authorized by law for fiscal year 1991, in order to ensure, at a minimum, a continuation of the vital services now provided, and, hopefully, to begin to expand services to the millions of women and teenagers in need of services who currently are not being served;
- that additional funding for HIV testing and counseling be targeted to family planning clinics as provided in last year's "pediatric AIDS initiative";
- that the Committee reiterate its intent that women seeking information about managing an unintended pregnancy in a federally supported family planning clinic be given nondirective counseling about all their legal options and referrals on request; and
- that a special supplementary fund of $10 million be provided specifically to boost the contraceptive development initiative already outlined by NICHD.

Senator **Harkin**. Sherry, thank you very much, again, for taking the time and effort to come this distance and to testify on behalf, not only of Planned Parenthood of Iowa, but also the Planned Parenthood Federation of America. And thank you for your very fine testimony.

I just have a couple of questions that I would like to explore with you.

Ms. **Bolt**. OK.

Senator **Harkin**. First, the administration has been trying to centralize operations and grant making for title X. As I understand it, they want to give the State grants and then have it centralized in one agency. And I understand in Iowa there are two grantees, Planned Parenthood of Iowa and the State health department.

Do you have any thoughts on this idea of centralization?

Ms. **Bolt**. I guess my main comment would be, we have 14 centers around the State, 3 in Des Moines and 11 around Iowa. We do this because it is very hard for our low-income patients to come to Des Moines, which of course, is where our largest centers are.

We find, in fact, in my travel over the last 2½ years, it has been very helpful. The patients have been very appreciative that they can go to the areas in their smaller towns and locations that are relatively easy for them to get there. To tell them that someone, for instance from Red Oak, should come to Des Moines for their basic health services, is not realistic. They just do not have the funds and the availability of transportation to the city.

In fact, our general feeling is that we should have more centers for health care and education. That really, every middle-sized town in Iowa should have facilities available so that the low-income patients can come right there, as opposed to having to worry about getting to one of the large cities.

Senator **Harkin**. As a strong supporter of title X funding and increased title X funding, I appreciate your pointing out that funds have been cut 17 percent in real terms in the last decade. And the need is even greater today than ever. Especially the cost on the clinics of running more tests for sexually transmitted diseases, and I guess the lab tests have gone out of sight.

Ms. **Bolt**. Absolutely.

Senator **Harkin**. Thus putting more of a burden on the clinics. Also, the $10 million that we put in last year for the pediatric AIDS counseling and testing, we will try it again. And hopefully, we will keep it this year, but you can rest assured that we will put it back in.

I understand Planned Parenthood is asking a recommendation of $171 million as the appropriation for title X this year. We had put in last year—what, $142? $142 million, and we had to compromise down to $139.1 million.

Ms. **Bolt**. I know. We are thinking positive.

Senator **Harkin**. Right, think positive. Also, let me explore just a minute with you the gag rules. Am I correct in understanding that a planned parenthood clinic counselor in a clinic cannot advise a person who comes in seeking advice, cannot even advise that person of the legal—the legal remedies or the legal options that are available?

Ms. **Bolt**. It absolutely frightens me to tell you that that is my impression, too. And when I am standing in the parking lot on Saturday mornings being picketed, when there are young girls who want to go in, not necessarily for abortion, but for some assistance, and to think that it is going to be very hard for them to—some of these girls—when I was 12 and 13, my lovely mother was still helping me across the street. And I am 52, and things, I recognize, have changed drastically. But to see a young girl go into the office hoping for some direction and assistance and to think—I was in the parking lot about 2½ years ago, and I had just locked my keys inside my car, and I was standing there bawling myself out and wondering how I could be so foolish. And a car came up with four young people in it, one young girl and three boys. The oldest one was 16, and he was the driver, and they decided—he decided he would have a cigarette while they got out of the car.

And the girl was very uptight and very concerned and very uneasy. And she was not even noticing that I was there. They were two cars over from me, but she was talking loudly enough that it was very easy for me to hear. And she was very uneasy and very glad to be there, and she was very appreciative that her friend, who was 16, had brought her, and she had talked with her mother about this.

And she had a boyfriend and that boyfriend had assured her if they were sexually active, because she did not want to have a baby, she would not become pregnant. And she now had missed two periods and she was afraid she might be. The concern and the—it was just so obvious.

She said, you know, my mother—I am the ninth child. I have never had a new dress. She said, and I do not even know who my daddy is. And do you know when I told my mama there might be a problem, do you know what she said? She said, honey, if you are pregnant, I will get you a container of vitamin pills.

Now, it just blew my mind. I mean, I hardly forgot. I could not get in my car and go home, because I could not get into it because the keys were inside.

It just terribly concerns me that we are overlooking so many—now, I do not know, the young girl could have gone in. I mean, at 13, it blows my mind to think that she might have been pregnant. But if she was, I certainly would want adult help. Her mother was certainly not being helpful, and I certainly would hope that some professional people could talk with her. If she was pregnant, she was going to have some major, major decisions to be made. She needed much more than a bottle of vitamin pills.

Senator **Harkin**. OK. That is a story that is just too often repeated, I think, all over the country, that these young girls are in. And I have a feeling a lot of times, people think that every family is like Ozzie and Harriet Nelson or the Huxtables.

Ms. **Bolt**. Exactly, exactly.

Senator **Harkin**. One of the two, and that is just not the case. I have a deep concern that planned parenthood's hands are being tied by these gag rules, that people are being intimidated, as you point out, from even coming in and seeking advice and help in the beginning. And if anyone is interested in reducing the number of abortions, this is the way to do it.

Ms. **Bolt**. Absolutely. It is our main goal; 94 percent of all of our services are quality health services for low-income women, and education. And we served just over 50,000 people last year.

Senator **Harkin**. Well, just from this one individual, I want to compliment you and Planned Parenthood Federation of America for all that you have done, to let you know that we will work and do whatever we can here to get that funding up and hopefully to get those gag rules lifted. Of course, those are in the courts now, being decided in the courts, but it just seems to me that planned parenthood ought to be able to advise a patient of all of their legal rights, whatever those legal rights are. And hopefully, in not too short a time, we will see that turn around.

Sherry, thank you very much for being here. I appreciate it.

Ms. **Bolt**. Thank you. I appreciate being here. Thank you very much.

STATEMENT OF ELEANOR WILCOX, SECRETARY, NORTH DAKOTA STATE LEGISLATIVE COMMITTEE

Senator **Burdick** [presiding]. The next witness will be Eleanor Wilcox, secretary of the North Dakota State Legislative Committee, American Association of Retired Persons.

I understand you hail from that great community in North Dakota called Devil's Lake.

Ms. **Wilcox**. Good morning, Senator Burdick. On behalf of the American Association of Retired Persons [AARP] thank you for this opportunity to testify concerning the administration's fiscal year 1991 budget request.

My name is Eleanor Wilcox, and I am secretary of the North Dakota State Legislative Committee. I will summarize the association's recommendations, Senator Burdick, and request that our complete statement be made part of the record.

AARP does recommend a significant restoration of funds to the Low-Income Home Energy Assistance Program, in the amount of $1.6 billion. If this is not possible, we urge the current service funding, at the very least. The administration's proposed reduction of more than $300 million below the current level would have a devastating effect on this program, Mr. Chairman.

Our own State of North Dakota would lose approximately $2.8 million under the proposal, and, Senator Burdick, you know it does get cold in North Dakota, and many of our older people are very much in need of this program. It was zero degrees with 18 inches of snow when I left yesterday, and then I was hoping for 80 degrees here, but I think you kind of pulled a fast one on me.

AARP does recommend that funding for programs authorized under the Older Americans Act, be continued at no less than current levels. We also recommend $7.8 million to implement the 1991 White House Conference on Aging.

For the Senior Community Service Employment Program, AARP recommends $398.8 million next year. AARP appreciates the subcommittee's support of this program over the years, and we urge current service funding for programs authorized under the Job Training Partnership Act.

Senator Burdick, we are very concerned about the proposal to charge user fees to long-term care providers for surveying and certification activities under the Medicare and Medicaid Programs. The next several years are particularly critical for nursing homes and for home health providers, who must meet the new Federal mandates. We will be contacting the subcommittee in more detail regarding this issue at a later date.

PREPARED STATEMENT

AARP supports the continued funding at the current service level for research conducted by the National Institute of Health. The 13 research centers, which comprise NIH, have played important roles in advancing, not only aging research but research to benefit all of our generations. We appreciate the subcommittee's careful consideration of these recommendations and stand ready to work closely with members and staff in any way.

Thank you, Senator Burdick.

[The statement follows:]

STATEMENT OF ELEANOR WILCOX

ON BEHALF OF THE AMERICAN ASSOCIATION OF RETIRED PERSONS (AARP), THANK YOU FOR THIS OPPORTUNITY TO TESTIFY CONCERNING FY1991 FUNDING FOR PROGRAMS UNDER THIS SUBCOMMITTEE'S JURISDICTION. MY NAME IS ELEANOR WILCOX AND I AM SECRETARY OF THE NORTH DAKOTA STATE LEGISLATIVE COMMITTEE.

AARP'S RECOMMENDATIONS CAN BE SUMMARIZED AS FOLLOWS:

1) PROVIDE A SIGNIFICANT RESTORATION OF FUNDS ($1.6 BILLION) TO THE LOW INCOME HOME ENERGY ASSISTANCE PROGRAM (LIHEAP); ENSURE, AT A MINIMUM, CURRENT SERVICES FUNDING ($1.45 BILLION)

2) PROVIDE NO LESS THAN FY 1990 FUNDING FOR OLDER AMERICANS ACT (OAA) PROGRAMS ADMINISTERED THROUGH THE ADMINISTRATION ON AGING ($747.4 MILLION).

3) RAISE THE FY 1991 APPROPRIATION FOR THE SENIOR COMMUNITY SERVICE EMPLOYMENT PROGRAM (SCSEP, TITLE V OF THE OAA) BY AN AMOUNT ADEQUATE TO ACCOMMODATE MINIMUM WAGE INCREASES FOR 65,804 AUTHORIZED PERMANENT POSITIONS ($398.8 MILLION).

4) PROVIDE A REALISTIC LEVEL OF FUNDING FOR MEDICARE CONTRACTORS.

5) PROVIDE SUFFICIENT FUNDING TO MAINTAIN CURRENT SERVICES IN THE GERIATRIC HEALTH CARE TRAINING PROGRAM AND NO LESS THAN THE CURRENT LEVEL OF RESEARCH SERVICES BY THE NATIONAL INSTITUTES OF HEALTH, PARTICULARLY IN THE FIELD OF AGING.

A. LOW INCOME HOME ENERGY ASSISTANCE PROGRAM (LIHEAP)

THE ASSOCIATION SUPPORTS RESTORATION OF LIHEAP FUNDING TO $1.6 BILLION. CUMULATIVELY, $1 BILLION WILL HAVE BEEN CUT FROM THE PROGRAM SINCE FY 1985 IF THE ADMINISTRATION'S PROPOSAL IS ADOPTED, DESPITE THE FACT THAT FEWER THAN 1/3 OF ELIGIBLE LOW INCOME HOUSEHOLDS ACTUALLY GET SERVED.

LIHEAP IS CRITICAL TO LOW INCOME OLDER AMERICANS, WHO ARE MOST VULNERABLE TO HEAT STROKE AND HYPOTHERMIA AND ARE THEREFORE GIVEN PRIORITY FOR SERVICE. OF THE HOUSEHOLDS RECEIVING WINTER

HEATING AND SUMMER COOLING ASSISTANCE, 38 PERCENT AND 56 PERCENT, RESPECTIVELY, HAVE BEEN OCCUPIED BY OLDER PERSONS. WHILE LIHEAP PAYS ONLY A PORTION OF THE ENERGY BILL FOR HOUSEHOLDS, THIS ASSISTANCE CAN MAKE THE DIFFERENCE BETWEEN ILLNESS AND HEALTH -- NEVER MIND BASIC COMFORT.

ENERGY PRICES CONTINUE TO RISE, ALTHOUGH NOT AS RAPIDLY AS IN THE EARLY 1980'S. MOST IMPORTANTLY, HOWEVER, LIHEAP ELIGIBLE HOUSEHOLDS ARE SIGNIFICANTLY POORER. THE PROPOSED CUT OF ALMOST $300 MILLION COULD MEAN ELIMINATING FROM THE PROGRAM OVER ONE MILLION HOUSEHOLDS AND FURTHER REDUCING BENEFITS THAT ARE ALREADY TOO LOW. CONTRARY TO POPULAR OPINION, MOST LIHEAP HOUSEHOLDS DO NOT RECEIVE OTHER FORMS OF PUBLIC ASSISTANCE, BUT ARE PART OF THE LARGE UNDERCLASS KNOWN AS THE WORKING POOR.

IN THE PAST IT HAS BEEN SUGGESTED THAT ALTERNATIVE FUNDING SOURCES FOR LIHEAP WOULD BE AVAILABLE, BUT THEY HAVE NEVER MATERIALIZED. TOTAL OIL OVERCHARGE MONIES SPENT ON LIHEAP HAVE NOT BEEN SUFFICIENT TO OFFSET THE TOTAL REDUCTION FROM THE FEDERAL FUNDS. IT IS NOT APPROPRIATE TO ASSUME THAT STATES EITHER PLAN, DESIRE, OR CAN AFFORD TO RESTORE FEDERAL LIHEAP CUTS.

B. OLDER AMERICANS ACT/ADMINISTRATION ON AGING

THE ASSOCIATION RECOMMENDS THAT FUNDING FOR OLDER AMERICANS ACT PROGRAMS BE CONTINUED AT NO LESS THAN FISCAL YEAR 1990 LEVELS. TODAY, MANY AGED PERSONS ARE ABLE TO LIVE INDEPENDENTLY IN THEIR OWN HOMES BECAUSE OF EFFECTIVE AND INNOVATIVE SUPPORTIVE SERVICES, MEALS, PROGRAMS, TRAINING, RESEARCH AND DEMONSTRATION PROVIDED BY THE ACT.

THE ASSOCIATION FURTHER RECOMMENDS AN APPROPRIATION OF $7.8 MILLION TO IMPLEMENT THE 1991 WHITE HOUSE CONFERENCE ON AGING. THIS TOTAL, WHICH SHOULD REMAIN AVAILABLE UNTIL EXPENDED, IS THE SAME AMOUNT --NOT ADJUSTED FOR INFLATION-- SPENT MORE THAN TEN YEARS AGO FOR THE 1981 WHITE HOUSE CONFERENCE. THE AMOUNT RECOMMENDED BY THE ASSOCIATION IS ALSO ROUGHLY ONE-THIRD LESS

THAN THE TOTAL ESTIMATED AS NEEDED IN A STUDY CONTRACTED EARLIER BY THE REAGAN ADMINISTRATION.

C. TITLE V SENIOR COMMUNITY SERVICE EMPLOYMENT PROGRAM AND JTPA

THE ASSOCIATION URGES THE SUBCOMMITTEE TO PROVIDE AT LEAST $398.8 MILLION FOR THE SENIOR COMMUNITY SERVICE EMPLOYMENT PROGRAM. THIS AMOUNT REFLECTS NEW, MANDATED WAGE INCREASES FOR MORE THAN 65,800 LOW INCOME OLDER AMERICANS WHO PARTICIPATE IN THIS ESSENTIAL ACTIVITY, AND WHO RELY HEAVILY ON THESE RESOURCES. THE ASSOCIATION APPRECIATES THE SUBCOMMITTEE'S STRONG SUPPORT OF THIS PROGRAM OVER THE YEARS. AARP ALSO URGES CURRENT SERVICES FUNDING FOR THE JOB TRAINING PARTNERSHIP ACT.

D. MEDICARE CONTRACTOR FUNDING

AARP URGES THE SUBCOMMITTEE TO PROVIDE A REALISTIC LEVEL OF FUNDING FOR MEDICARE CONTRACTORS IN FISCAL YEAR 1991. CONTRACTORS ARE RESPONSIBLE FOR REIMBURSING MEDICARE BENEFICIARIES AND PROVIDERS, AND PROVIDE TECHNICAL ASSISTANCE AND INFORMATION ABOUT CHANGES IN THE MEDICARE PROGRAM. WITHOUT REASONABLE FUNDING, WE CAN EXPECT FURTHER DELAYS AND ERRORS IN PROCESSING PAYMENTS FOR BENEFICIARIES AND PHYSICIANS.

E. NURSING HOME INSPECTIONS

THE ASSOCIATION IS VERY CONCERNED ABOUT THE PROPOSAL TO CHARGE LONG-TERM CARE PROVIDERS "USER FEES" TO BE SURVEYED AND CERTIFIED FOR PARTICIPATION IN THE MEDICARE AND MEDICAID PROGRAMS. THE NEXT SEVERAL YEARS ARE PARTICULARLY CRITICAL FOR NURSING HOME AND HOME HEALTH PROVIDERS WHO MUST MEET NEW REQUIREMENTS FOR ASSURING QUALITY OF CARE AS STIPULATED IN THE 1987 OMNIBUS BUDGET RECONCILIATION ACT. MANY OF THESE PROVISIONS ARE SLATED TO TAKE EFFECT THIS YEAR. THE ASSOCIATION WILL BE CONTACTING THE SUBCOMMITTEE IN MORE DETAIL CONCERNING THIS PROPOSAL AT A LATER DATE.

F. GERIATRIC TRAINING

AARP SUPPORTS FUNDING SUFFICIENT TO MAINTAIN CURRENT SERVICES FOR FEDERAL PROGRAMS IN GERIATRIC HEALTH CARE TRAINING. THE RAPIDLY AGING POPULATION AND THE ESTIMATED SHORTAGE IN HEALTH CARE PROFESSIONALS UNDERSCORE THE NEED FOR FEDERAL SUPPORT OF GERIATRIC TRAINING.

G. NATIONAL INSTITUTES OF HEALTH

AARP SUPPORTS CONTINUED FUNDING AT THE CURRENT SERVICES LEVEL FOR RESEARCH CONDUCTED BY THE NATIONAL INSTITUTES OF HEALTH (NIH). THE THIRTEEN RESEARCH CENTERS WHICH COMPRISE NIH HAVE PLAYED IMPORTANT ROLES IN ADVANCING NOT ONLY AGING RESEARCH, BUT RESEARCH TO BENEFIT ALL GENERATIONS. AS THE POPULATION AGES, CRUCIAL POLICY DECISIONS WILL HAVE TO BE MADE IN EVERY SECTOR. IT IS ESSENTIAL THAT THESE DECISIONS BE GROUNDED IN SOLID RESEARCH. THE ASSOCIATION APPRECIATES THE IMPRESSIVE WORK DONE BY THE NIA IN THIS REGARD.

AARP APPRECIATES THE SUBCOMMITTEE'S CAREFUL CONSIDERATION OF THESE RECOMMENDATIONS AND STANDS READY TO WORK CLOSELY WITH MEMBERS AND STAFF AS YOU PROCEED TOWARD MARKUP OF A BILL FOR FY 1991.

PROPOSED CUT IN LIHEAP

Senator BURDICK. Thank you. Could you tell me something about the administration's proposed cut in LIHEAP? What would it mean to your hometown of Devil's Lake in North Dakota?

Ms. WILCOX. It could be very serious, Senator Burdick, because I have worked as an outreach worker for many years in our area. We find a lot of our older people that are trying to stay in their own homes as long as possible, and their need is certainly there.

This winter we had quite a nice winter for North Dakota. But we did have a week of 30 below, and you know what that can do. And so, their fuel reserves were used up very fast this year. So, it would be a devastating effect on our State, I know.

Senator BURDICK. We appreciate your appearance here this morning, and we thank you for coming.

Ms. WILCOX. Thank you, Senator.

STATEMENT OF JAMES P. PRESLOCK, CHAIRMAN, PUBLIC AFFAIRS COMMITTEE OF THE SOCIETY FOR THE STUDY OF REPRODUCTION

Senator **Burdick**. The next witness will be James Preslock, Society for the Study of Reproduction. Welcome to the committee.

Dr. **Preslock**. Senator Burdick, distinguished members of the subcommittee, ladies and gentlemen, my name is Dr. James Preslock. I am a biomedical research scientist and associate professor in the Department of Obstetrics, Gynecology, and Reproduction Sciences of the University of Texas Medical School and Health Science Center in Houston, TX. I serve as the chairman of the Public Affairs Committee for the Society of the Study of Reproduction.

Our society is deeply concerned by the continuing crisis in the funding of basic and applied research in the reproductive sciences as funded through the National Institute of Child Health and Human Development. And, we are also concerned by the low rate of funding of new research grants, funded through the National Institutes of Health.

The NIH, including the NICHD, is currently funding new research grants at the lowest level in over a decade. During 1990, the NIH will fund only 4,633 new research grants, while the NICHD will fund only 323 new grants. Superimposed upon this low rate of funding are high downward negotiations, which will average 12 percent per grant.

Since 1987, which was a banner year, the NIH, overall, has decreased its funding of new research grants by 28 percent, while the NICHD has decreased its funding of new grants by over 40 percent.

Unfortunately, the President's budget submitted for 1991 provides virtually no relief. For the NICHD, the President would fund only 362 new grants, and for the NIH as a whole, the President's budget would fund only 5,095 new research grants.

The Society for the Study of Reproduction is opposed to the President's budget of $461 million for the NICHD for 1991, and we instead recommend a budget of $635.3 million. Under this budget, the number of new grants which would be funded, would increase from 323 under the President's budget proposal, to 644. The funding rate will increase from 22.5 percent to 40 percent of approved grants and with no downward negotiations.

This budget would also increase the number of NICHD centers from 53 to 60 and with no downward negotiations. This budget would also fund 1,069 noncompeting grants at full cost, and would increase the number of individual and institutional trainees from 690 to 800.

We recommend to the subcommittee, if these goals are not attainable under current budgetary restraints, that we work together to embark on an upward path so we may attain these budgetary and grant funding goals within the next 2 years.

In general terms, this budget would provide much-needed grant funding to investigate disorders to the reproduction system, including menopause, infertility, development of new contraceptives, and it would alleviate the chronic problem of the underfunding of the NICHD as an Institute of the NIH.

For the NIH as a whole, we recommend a budget of $9.237 billion for 1991. This level of funding would increase the number of new grants to a baseline level of at least 6,500, would provide for a desirable funding rate of approximately 40 percent of approved grants and with no downward negotiations.

This level of funding for the NICHD—the NIH, including the NICHD, would do much to stem the flow of scientists from the biomedical sciences. It would also greatly encourage young people to enter into the biomedical sciences as a career choice.

The budget proposal of the President would only serve to continue to discourage biomedical research as a scientific discipline. If we wish America to be a strong and a vital center for advances in biomedicine throughout this decade and into the next century, the time for action is now. The decision is yours, and I hope that you will support in appropriations what I propose to you.

Thank you.

Senator BURDICK. Thank you, Doctor.

What will be the effect of the program if we do not increase the funds as you request?

Dr. PRESLOCK. Well, the effect we will have is that we will continue to have a very low rate of funding. See, the problems that we are having now in the research community, both at the university level and the research institute level, is that with the low rate of funding being as low as it is, not only for the National Institutes of Health overall, but also, specifically for the Child Health Institute, is it is having a very chilling effect on young people entering into biomedical sciences, because they see that they not only have to spend a large number of years, 5, 6, perhaps 7 years beyond the baccalaureate degree, to get an M.D. degree or a Ph.D. degree, and then the thought of going into biomedical research with the possibility of not getting grant funding is very discouraging, because the acquisition and the possession of grants are extremely important in the academic community, not only in terms of one's prestige but in terms of one's scientific and professional advancement.

And also, another problem that we are having is people who are mid-career and also further along, established investigators, are also losing their grant support, and they are either being discouraged from continuing in this area, or they are seeking other areas of disciplines, with the funding situation being as bad as it is right now.

Senator BURDICK. Let me ask you in a different way. What will be the effect on the country and the community, if the money is not granted?

Dr. PRESLOCK. Well, I think overall, if we start, as I mentioned in my testimony, sir, if we start a trend of starting to go back upward, 1987 was considered a banner year for the NIH. At that time the NIH, and I will kind of keep my comments to the overall National Institutes of Health, that was considered a banner year. The NIH, during that year, supported and funded approximately 6,500 new grants.

Now, during the Carter administration, approximately 10 years ago, the 6,500 grants was pretty well disseminated through the research community as being a stable level that the NIH would fund. At the time, when that level was put out, it was thought of that this would be a basement level, that that would be the least number that the NIH would fund. And now what we are looking at is 6,500 grants being kind of the upper level that the NIH would fund.

So, if we do start funding this and we do start bringing the National Institutes of Health and all the Institutes within the National Institutes of Health, of course, including the NICHD, I think in time, what we are going to start seeing is the biomedical sciences being a more attractive place for people to go, and of course, the overall effect is that we will greatly advance biomedicine, health care, treatment of disease, and these type of issues.

Senator **Burdick**. Thank you very much, Doctor.

Dr. **Preslock**. Thank you, sir.

STATEMENT OF DONALD J. HEIM, CHAIRMAN AND CEO, WASHINGTON GAS LIGHT CO. ON BEHALF OF THE AMERICAN GAS ASSOCIATION

Senator **Burdick**. Our next witness will be Donald Heim, American Gas Association.

Welcome to the committee.

Mr. **Heim**. Mr. Chairman, I am Donald Heim, chairman and chief executive officer of the Washington Gas Light Co.

Washington Gas distributes natural gas in the greater Metropolitan Washington area. I am appearing here on behalf of the American Gas Association, which is a national trade association of some 250 natural gas distribution and transmission companies, an organization of which I happen to be chairman this year.

I am here today to acknowledge the leadership of this subcommittee and the kind of leadership that it has provided, over the years, in support of LIHEAP, and to urge you to restore the LIHEAP funding to the level of $1.8 billion.

For fiscal year 1991, the administration proposes only $1.05 billion for LIHEAP, which is a $343 million cut from the current year. LIHEAP funding has already declined by a cumulative 30 percent since 1985, putting the program into a very tenuous situation. Even at the current funding levels, the benefit per family is about $200 per year versus about $1,000 in energy cost. A further cut will threaten its very existence.

As this subcommittee decides whether the LIHEAP Program deserves the continued Federal involvement, let me stress these facts. LIHEAP funding cuts affect all energy consumers. When low-income consumers cannot pay, utilities typically must pass along these costs to all other ratepayers.

The administration is flat wrong in asserting that LIHEAP funding should be reduced because of stable fuel prices. Regardless of the stability of fuel prices, LIHEAP participants still spend an unduly large portion of their family income on energy, four times as much as the remainder of American households.

The AGA recently conducted a telephone survey of State energy offices, and it showed that most States do not supplement LIHEAP funds with State or local funds. There are, of course, a number of private sector programs, but they can only supplement and not supplant LIHEAP funding.

For example, at Washington Gas, we could see a long time ago a need where LIHEAP funding was not adequate. Thus, in 1983 we organized the Washington area fuel fund to pick up the slack. WAFF is funded primarily by our ratepayers. More than 81,000 of them have contributed over the period of time. In its 7 years of existence, WAFF has raised more than $3.7 million and has helped more than 54,000 people stay warm in the winter. But programs like WAFF cannot pull the whole load for LIHEAP.

Please note these figures. In 1989, LIHEAP provided over $2.7 million in our service area, while WAFF provided $589,000. LIHEAP reached some 10,442 customer accounts, whereas, WAFF reached only 2,200. The fact is that in the greater Washington area, LIHEAP takes care of about five times as much of the need as does the voluntary WAFF program.

PREPARED STATEMENT

In conclusion, despite the useful efforts of fuel fund programs and other financial support from the private sector, the need for adequate Federal funding of LIHEAP remains imperative. On behalf of the American Gas Association and its member companies, I respectfully urge you to support our recommendation to fund LIHEAP in the level of $1.8 billion for fiscal year 1991.

I thank you for your attention, sir.

[The statement follows:]

STATEMENT OF DONALD J. HEIM

Introduction

Mr. Chairman and members of the Subcommittee:

I am Donald J. Heim, Chairman and Chief Executive Officer of the Washington Gas Light Company (WGL). WGL distributes natural gas in the metropolitan Washington, D.C. area through three operating divisions (District of Columbia Natural gas, Maryland Natural Gas and Northern Virginia Natural gas). I also serve as Chairman of the American Gas Association (A.G.A.).

A.G.A. is a national trade association of some 250 natural gas distribution and transmission companies. Natural gas is the home heating fuel for over 49 million households in the United States.

On A.G.A.'s behalf, I am pleased to have this opportunity to appear before the subcommittee in support of the Low-Income Home Energy Assistance Program (LIHEAP).

A.G.A. member companies are deeply committed to meeting the energy needs of all of our consumers, including those who are on lower or fixed incomes. A.G.A. has long supported federal energy assistance programs such as LIHEAP and the Department of Energy weatherization program. In addition to supporting federal funding efforts, A.G.A.'s member companies have contributed significantly to low-income energy assistance at the local level.

We in the natural gas industry urge you and other Senators to fund LIHEAP at a level of at least $1.8 billion for FY 1991. While this is more than our request for last year, it is more than four million dollars less than the proposed authorization of $2.15 billion in H.R. 4151. To date, there has been no reauthorization bill introduced in the Senate. As you are aware, for FY91, the Administration proposed only $1.05 billion for LIHEAP, a 25 percent cut over the appropriation for the current year.

A.G.A. supports a LIHEAP program that is adequately funded. Most studies on the low-income energy problem indicate that past LIHEAP funding levels, including the highest annual appropriations of $2.1 billion in FY 1985 and $2.0 billion in FY 1986, have fallen significantly short of the need for fuel assistance. Presently, only a small portion of these consumers' total energy costs are covered by LIHEAP. In its 1988 report, the Northeast Midwest Coalition indicated that for 1987, LIHEAP funds covered only 19.5 percent of the energy costs for eligible households. Moreover, according to statistics provided by HHS, only from 25 to 35 percent of all eligible households received LIHEAP funds in FY87. An estimated 18 million households in this country need some help paying these bills. Even in its peak year, LIHEAP reached only about one-third of these households, between five and six million. The average LIHEAP benefit is about $200 a year, versus about $1,000 in energy costs. Ideally, LIHEAP funding should be sufficient to ensure that low-income families have a reasonable opportunity to meet their energy bills.

LIHEAP Funding Cuts Affect All Energy Consumers

The lack of adequate funding will affect all ratepayers, because adequate funding of LIHEAP plays an important role in keeping bills somewhat realistic for all consumers.

Many low-income consumers who do not receive energy assistance, in many cases, simply cannot pay their utility bills. With the mandated and voluntary moratoria on utility service terminations in most states during the winter months, these consumers continue to receive gas service at least through the winter. Utilities attempt to work out a manageable plan for these consumers. However, if not successful, the customer gets further and further behind and the cost of providing gas service without payment is ultimately considered part of a utility's cost of service. This becomes a burden that is borne by all utility consumers.

There is another class of consumer whose plight is worsened by reduced federal funding, and these are the virtually millions of consumers who are on the fringe of LIHEAP eligibility. Often referred to as the "working poor", they may "percolate" in and out of poverty but are currently able to meet their energy costs without LIHEAP. However, an increase in energy costs or an increase in the number of days of cold weather will place these households in the same inability to pay situation that faces LIHEAP-eligible households today. Furthermore, reduced LIHEAP funding also forces many states to tighten eligibility requirements, throwing more of these consumers into a true energy crisis.

Two misconceptions that the Administration would have Congress accept as fact in justifying further LIHEAP cuts must be rebutted. First, the Administration states that energy prices are stabilizing, thus lessening the need for federal fuel assistance. Second, the Administration asserts that there are supplemental sources of fuel aid funding that lessen the impact of lower LIHEAP funding.

Stable Fuel Prices Do Not Reduce The Need For Adequate LIHEAP Funding

To millions of low-income consumers, LIHEAP is a badly needed safety net. The fact that fuel prices have stabilized as compared to fuel costs prevailing at the time LIHEAP was created overlooks the fact that LIHEAP recipients still spend an unduly large portion of family income for energy. Studies have repeatedly shown that low-income families pay a much greater share of their incomes for energy costs than do other families. According to the most recent Department of Health and Human Services (HHS) Report to Congress on LIHEAP (covering the years through 1988), households with incomes below 125 percent of the poverty level spend approximately four times the amount of their income (13.2 percent) for energy than the remainder of American households (3.4 percent).

Last year, A.G.A. conducted a phone poll of state LIHEAP administrators, with responses covering programs in 45 states. The responses show that the majority of states do not supplement LIHEAP with state or local energy assistance funds and we are concerned about this. More than half of the respondents anticipated a shortfall of LIHEAP funding in their states during the 1988-1989 heating season. While 18 states were identified as not expecting a shortfall of funds for the 1988-1989 heating season, some of the reasons given lend additional support for increased LIHEAP funding: 5 respondents indicated their states were going to cut benefits; 4 states would see their programs reaching fewer applicants; and 2 other states planned to initiate other unspecified program changes in response to reductions in federal LIHEAP funding.

Finally, part of the fuel price stability actually relates to fuel consumption, which directly correlates with the relatively mild winters we have experienced during the past two heating seasons. Congress should recognize that a return to normal or below normal weather next year would lead to increase fuel consumption which, in turn, would cause an increased in the percent of income devoted to home heating.

Supplies From Oil Overcharge Funds Are Only Temporary

Another of the Administration's rationales for further cuts in LIHEAP is the purported availability of funding from other sources to fill the gap. The so-called oil overcharge funds are frequently cited as examples of such supplemental funds. Congress should note that the impact of oil overcharge funds resulting from court decisions in U.S. v. Exxon and Stripper Well are virtually gone. Further, these monies supplement rather than supplant fuel aid programs. A February 1989 Report by the National Consumer Law Center estimates that 95 percent of all overcharge funds that were available nationwide have now been allocated by the states for a variety of uses. A total of $2.9 billion oil overcharge funds were allocated between 1986 and January, 1989. Of this amount, LIHEAP received only $590 million. During that same time period, LIHEAP saw a cumulative cut in federal appropriations of $1.652 billion. Therefore, the existence of oil overcharge funds should have no bearing on the amount Congress appropriates for LIHEAP.

Existing Utility Programs Can Only Supplement LIHEAP Funding

I do not want to imply that the burden of the low-income consumers' needs rests solely on the shoulders of the federal government. The states and the private sector also have a responsibility and do contribute significantly to the needs of these consumers. A.G.A. member companies have developed several innovative and effective programs in this area, including hiring social workers to bring together all the available resources in the community, developing budget counseling programs, and instituting a variety of crisis activities. The experience of Washington Gas Light and its Washington Area Fuel Fund (WAFF) is outlined in my oral presentation.

Since the late 1970s, many A.G.A. member companies have created and helped finance private fuel fund programs and weatherization projects in an effort to supplement LIHEAP and other federal programs. A recent survey sponsored jointly by A.G.A., the National Fuel Funds Network and the Edison Electric Institute provides a statistical portrait of the utility fuel fund programs of 121 respondents. The study clearly establishes that utility fuel funds are providing some measure of support for low-income households. In fact, the respondents reported that, since inception of utility fuel fund programs, they have distributed approximately $131.42 million to approximately 857,527 households. (Because many funds permit a household to receive benefits more than once annually, the number of households data could actually double count recipients.) In the 1987 reporting year, the respondents distributed $31.02 million to 193,081 households, with grants averaging $160.68 per household, and the average fund distributing $274,551. Of course, programs like WAFF and these utility fuel funds cannot do the whole job. Indeed, although they represent generous private sector support, utility fuel funds do not even being to approach the support needed at the federal level through LIHEAP.

Despite the efforts of A.G.A. member companies' fuel fund programs and other financial support from the private sector, the need for adequate federal funding of LIHEAP remains imperative.

Conclusion

Certainly, both the private and public sector must be prudent managers of spending. This is why during reauthorization hearings we requested that some changes be made to the statute. First, we urged that the ability of states to transfer up to 10 percent of LIHEAP funds to other programs be eliminated from the law. Second, we urged that the current carryover level of 15 percent to the next fiscal year be reduced, so that the needs of low-income households and the states' monetary requirements for instituting LIHEAP programs each heating season will be met. Lastly, we urged that LIHEAP payments be made directly or indirectly to the vendor or utility. We believe these changes will help stretch the budget dollars that are allocated for LIHEAP.

On behalf of A.G.A. and its member companies, I respectfully urge you and your fellow Senators to support our recommendation to fund LIHEAP at the level of $1.8 billion for FY91.

Thank you for your time today.

Senator BURDICK. Thank you. Under your proposed budget for LIHEAP, how many families would be served, and would all those be needy families?

Mr. HEIM. Yes; all of the families that areserved by the LIHEAP Program are administered through the States. And incidentally, there were a number of States that were precariously low on their funding during December of last year, which was a very cold period, including States in New England and North and South Dakota, and even Iowa. They were running precariously low in only the first month of the winter.

Senator BURDICK. How many families would be served?

Mr. HEIM. How many families have we served?

Senator BURDICK. The LIHEAP budget, your budget.

Mr. HEIM. In our franchise area, we had a figure where we served 10,442 customers with the LIHEAP Program, and 2,200 under the voluntary WAFF program.

Senator BURDICK. Has the AGA contributed any of its own funds to low-income families?

Mr. HEIM. The American Gas Association, to my knowledge, has not, but the member companies have, and my company, for one, has contributed each year that we have conducted the WAFF program.

Senator BURDICK. Thank you.

Mr. HEIM. Thank you, sir.

STATEMENT OF GLENN KIRKLAND, PRESIDENT, THE ALZHEIMER'S ASSOCIATION

Senator BURDICK. The next witness will be Glenn Kirkland, Alzheimer's Association.

Welcome to the committee.

Mr. **Kirkland**. Thank you, Senator Burdick. My name is Glenn Kirkland. I am a volunteer with the Alzheimer's Association and was the founding president of the Baltimore chapter.

I am here because I have a keen, personal interest in seeing that one day we will soon be rid of this scourge called Alzheimer's disease, because my concern stems from the fact that my wife, a beautiful, dynamic, very pleasant woman, healthy, was stricken 13 years ago with this scourge, and is now approaching, sadly, her terminal phase.

By way of background, Alzheimer's Association is the only national volunteer organization committed to finding a cure for Alzheimer's disease and easing the burden for the patients and for their caregivers, their loved ones.

The association works through a network of more than 2,000 chapters with more than 30,000 volunteers. Through this nationwide network, the association sponsors more than 1,600 family support groups, which provide a forum for families and friends to share information, as well as to receive valuable guidance on medical, nursing, respite care services available in the community.

This year marks the 10th anniversary of the founding of our organization. As you know, this subcommittee played an important part in this history. In fact, the first time that Alzheimer's was addressed at the national level was as a result of the action taken by this subcommittee. But a great deal has happened since then, since those early days.

For one thing, the level of research has increased from $13 million to about $130 million, and this in turn has led to a tenfold increase in the number of scientists investigating this disease.

But something else has changed. Last November, researchers completed a major study, and they found that more than 10 percent of the population over the age of 65 and nearly one-half of those over 85 suffered from Alzheimer's. According to the National Institute on Aging, this means that more than 4 million Americans, nearly twice as many as previously thought, are afflicted with this disease.

Unfortunately, whatever hope and promise exist may never be realized simply because there is not enough funding. Even though there is a cadre of well trained scientists prepared to enter this field of investigation, only one out of every five high quality grant proposals received by NIH for Alzheimer's research can be funded.

So, our recommendation, Mr. Chairman, is that we urge you to earmark $300 million for research on Alzheimer's disease this year. This amount is consistent with the professional judgment of the National Institute on Aging, as well as the recommendations of the National Advisory Panel on Alzheimer's Disease.

While this amount may seem large, it is the amount needed. Please keep in mind that NIH is currently investigating 5 to 10 times the current Alzheimer's budget for each of the following: cancer, heart, and AIDS research, despite the fact that the social and economic impact of Alzheimer's is about the same order of magnitude of each of these diseases.

In the way of perspective, last year Americans spent $200 million to celebrate the Fourth of July by buying fireworks; $300 million was earned by the top 10 movies in the last 10 weeks; $700 million was taken in by the Maryland State Lottery. Last year—I mean in the year of 1985, more than $1,000 million was spent on chewing gum.

PREPARED STATEMENT

So, while we appreciate the difficult task facing the subcommittee, on the other hand, we fully believe that the problem of this size and magnitude warrants applying the resources that we have recommended. So, we hope that you will give our request full consideration when the subcommittee marks up the Labor-HHS bill.

I would be pleased to answer any questions you might ask.

[The statement follows:]

Statement of Glenn Kirkland

Mr. Chairman and members of the subcommittee—my name is Glenn Kirkland and I am here on behalf of the Alzheimer's Association. I was also the founding President of the Association's Baltimore Chapter.

Mr. Chairman, I am here because I have a deep personal interest in seeing that one day soon we are rid of this horrible affliction known as Alzheimer's disease. My concern stems, in large part, from the fact that my wife Grace, an otherwise bright, dynamic, and healthy woman, has been stricken with Alzheimer's disease.

By way of background, the Alzheimer's Association is the only national voluntary organization committed to finding a cure for Alzheimer's disease and easing the burden of patients, their families, and loved ones. The association works through a network of more than 200 chapters, 1,600 support groups, and over 30,000 volunteers.

Through this nationwide network, the Alzheimer's Association sponsors family support groups and provides a forum for families and friends to share information and receive valuable guidance on medical, nursing, and respite care available in the community.

Mr. Chairman, this year marks the tenth anniversary of the founding of our association. And you should know that this subcommittee plays an important part in our history. In fact, the first time Alzheimer's disease was addressed at the national level came as a result of actions taken by this subcommittee.

A great deal has happened since those early days. For one thing, the level of research funding has grown, from $13 million to $130 million. This, in turn, has led to a tenfold increase in the number of scientists investigating this disease. But something else has changed—something that threatens to hemorrhage our society.

Researchers last November completed a major study that found more than 10 percent of people over age 65 and nearly one-half of those over 85 suffer from Alzheimer's disease. According to the National Institute on Aging, that means 4 million Americans, nearly twice as many as we previously thought, are afflicted with Alzheimer's disease. And given the projected growth of the elderly population, the institute now projects that 14 million Americans could be stricken by the middle of the next century.

Mr. Chairman, Alzheimer's disease is already costing this nation well over $90 billion. The new estimates mean that in the future this disease will drain many times that amount from our economy, not to mention the strain it will place on our families and our health care system.

You recently heard Dr. Williams of the Aging Institute say that answers—once thought to be decades away—could come much sooner. Some of the more exciting research opportunities he highlighted could lead to early identification and diagnosis of the disease, more effective strategies for treating Alzheimer patients, and drug therapies that can half the progress of Alzheimer's at its earliest stages.

Unfortunately, whatever hope and promise exists may never be realized simply because of inadequate funding. Even though there is a cadre of well-trained scientists prepared to enter this field of investigation, the NIH is unable to fund 4 out of every 5 high-quality grant proposals relating to Alzheimer's disease. And as was pointed out during the subcommittee's recent hearings, several promising new drugs will go untested because of lack of funds.

RECOMMENDATION

Mr. Chairman, we urge you to earmark $300 million for research on Alzheimer's disease. This amount is consistent with the professional judgment budget of the NIA and the recommendations of the National Advisory Panel on Alzheimer's Disease. And while this amount might seem to be a large increase, that is just what is needed. Please keep in mind that NIH is investing 5 to 10 times more for research on other major diseases, like cancer, heart, and AIDS, despite the fact that the social and economic costs of Alzheimer's disease are on the same or sometimes greater order of magnitude.

While we appreciate the difficult task facing you and your subcommittee, we believe that a problem of this size and tragic impact warrants the resources we have recommended. We hope you will give this request full consideration when the subcommittee marks up the Labor-HHS bill.

Thank you, Mr. Chairman. I would be pleased to answer any questions you may have.

Senator **BURDICK**. Could you tell me what advance has been made in the stopping or controlling or limiting Alzheimer's disease in this country?

Mr. **KIRKLAND**. Very little so far, sir. It is a difficult disease, as you probably know, because of the nature of it. The cause is not known, and so, therefore, we do not have any way of guessing what a cure is. So, we are anxious to identify the cause and to see what chemicals, what drugs can be used to ameliorate the symptoms of the disease.

Senator **BURDICK**. Thank you.

STATEMENT OF VIVIAN L. FULLER, NATIONAL YOUTH SPORTS PROGRAM COMMITTEE, NATIONAL COLLEGIATE ATHLETIC ASSOCIATION

ACCOMPANIED BY AARON MOORE

Senator **BURDICK**. Our next witnesses will be Vivian Fuller and Aaron Moore, NCAA National Youth Sports Program. You may proceed.

Ms. **FULLER**. Good morning. My name is Vivian L. Fuller, chairperson of the NYSP National Youth Sports Program. I have submitted in writing a prepared speech for you for the record, and will be happy to answer any questions.

But today, I would like for you to hear from a former NYS participant, Aaron Moore.

Mr. **MOORE**. Thank you.

Good morning. My name is Aaron Moore. I am currently a graduating senior from Tennessee State University majoring in computer science. I have a 3.7 grade point average.

Today, I would like to share with you my experiences through the National Youth Sports Program and the exposure that it has given me in making the transition from the environment of Sheridan Road SE., to a collegiate program.

I am the youngest in a family of nine children. I grew up in Southeast Washington. I am also first-generation college. I come from a single parent household, in which my mother often had to work two jobs to support the family; therefore, there was very little parental guidance.

I have always had a very strong academic background, but because of the misconceptions and limited exposure of my environment, I never thought that I could go far in academia.

There were very few role models in my environment and for me, succeeding in the streets was my most important objective. Sheridan Road SE., that one-quarter mile strip of land was the world to me, in essence. This was an environment where most considered graduating from junior high school as being the pinnacle of achieving success.

I feel often that I am a kindred spirit with most of the problem youth that you read about today in the newspapers, because a lot of their activities were the same types of activities that I was involved in. My only advantage was the National Youth Sports Program.

The National Youth Sports Program was a completely new experience for me. For the first time, I was taught to discover my talents and ability, and also taught how to use those talents and abilities and channel my energies in positive directions. It was a very positive outlet for me.

The NYSP also provided very positive exposure through the enrichment programs daily, in which we participated in classes which taught about the harmful effects of drug abuse, it talked about teenage pregnancies, it talked about career decisions and career goals.

As a result of my involvement with the National Youth Sports Program, my accomplishments thus far, I was capable or enabled to successfully combine athletics and academics in achieving my life's ambitions. I was taught to use athletics as a vehicle, and as a result I graduated salutatorian and most outstanding athlete in my high school. I was selected as most outstanding athlete, student athlete at Tennessee State University for 2 years.

Upon graduation, I have numerous employment opportunities with IBM, Digital Equipment Corp., Bell Corp. and Bell Labs and also the opportunity to pursue graduate school.

PREPARED STATEMENT

In conclusion, I would just like to say that the National Youth Sports Program is more than just another recreational program. The National Youth Sports Program inspires young people to achieve their goals and ambitions in life, and teaches that success is based on more than monetary values or materialistic values, but is based on the development of a well-rounded character.

With sports programs like the National Youth Sports Program, we inspire leaders for tomorrow. Without, we impact a serious detriment to the future of our country. Thank you.

[The statement follows:]

STATEMENT OF VIVIAN L. FULLER

Mr. Chairman and members of the Subcommittee, my name is Vivian L. Fuller. I am Associate Director of Intercollegiate Athletics at Indiana University of Pennsylvania and a member of the National Collegiate Athletic Association ("NCAA") National Youth Sports Program ("NYSP") Committee. Previously, I was Activity Director of the NYSP project at North Carolina A&T State University in Greensboro, North Carolina, for two years and a project aide at the NYSP project at Fayetteville State University in Fayetteville, North Carolina, for four years. Joining me today is Aaron Moore, a senior honors student with a 3.7/4.0 grade point average majoring in computer science at Tennessee State University. Aaron participated in the NYSP project at the University of the District of Columbia from 1978-1982 and worked there as an NYSP staff member from 1983-1985. We appreciate this opportunity to testify in support of an FY 1991 NYSP appropriation of $14.65 million.

First, I would like to express the deep appreciation of the NCAA, and my own personal thanks, for the continued congressional support for this nationally recognized program. Your generous actions have enabled hundreds of thousands of young people from poverty areas to participate in the NYSP.

This Subcommittee knows well the basic facts concerning this outstanding program. Each year for more than 20 years, the NYSP has brought tens of thousands of economically disadvantaged boys and girls, ages 10-16, onto college and university campuses nationwide. NYSP participants receive a free medical examination and follow-up; free daily USDA-approved meals; high quality instruction in competitive and lifetime sports; and enrichment instruction in drug and alcohol abuse prevention, health and nutrition, educational and career opportunities, teen pregnancy, AIDS, and other topics. For example, NYSP projects in Los Angeles, where gang violence is prevalent, provide instruction concerning the destructive nature of gang activities. In 1989, an estimated 67,000 boys and girls participated in NYSP summer and extended program projects at 135 colleges and universities (30 percent of which are not NCAA members and one-third of which are historically black institutions) in 113 cities in 42 states.

Each higher education institution participating in the NYSP donates high quality educational and sports facilities, equipment, and the services of a project administrator. The NCAA administers the program on a national basis without charge. The NCAA also helps to generate contributions from private corporations, including Rawlings Sporting Goods Company, Tachikara (a subsidiary of Arch Billmire Company), and Penn Athletic Products. No federal funds are allocated to the NCAA or to individual institutions for overhead. In 1989, we estimate that the non-federal matching contributions to the NYSP exceeded $19.5 million. By combining federal, state, local, and private resources, the NYSP again was able to provide more than $3 in high-quality benefits and services to needy youngsters for each federal dollar appropriated.

Over this past year, we have taken many steps to make drug abuse prevention a major focus of the NYSP. We are excited by this new effort, because the NYSP is particularly well-positioned to help stem drug abuse by youngsters. The disadvantaged young people served by the NYSP are a key target population for efforts to reduce the demand for illegal drugs. The program offers both a constructive alternative to drugs and, as part of the enrichment component, anti-drug abuse instruction and counseling.

An important element of this increased anti-drug abuse emphasis, discussed in greater detail below, is the Extended NYSP, which is conducted during the period from October to May. The extended program was initiated in October 1989 on a pilot basis at 45 college and university campuses. In 1990, ten more Extended NYSP projects will be established. Other steps we have taken include the hiring of a drug education specialist for each NYSP summer and extended program project, training other NYSP personnel in drug abuse prevention techniques, doubling the amount of instruction devoted to substance abuse prevention, and establishing several new NYSP summer projects in areas such as Los Angeles.

The Extended NYSP, which includes a broad spectrum of sports and enrichment activities, allows projects to maintain contact with participants and to continue delivering the NYSP's anti-drug abuse message throughout the year. In addition, it provides a unique opportunity for youngsters to be on campus during the academic year when the college or university is in full operation, students are on campus, and more resources and opportunities are available. The first year of the Extended NYSP has demonstrated the great potential of this new aspect of the program.

Our appropriation request this year is based upon the needs of the NYSP and steps that we think should be taken to realize more fully the potential of the program. Increased funding received in the last several years has helped to restore some lost services and has significantly enhanced the anti-drug abuse component of the program. Many basic services, however, such as transportation and medical follow-up, have yet to be restored to past levels.

In addition, salary ceilings, in place since 1985, are impeding our ability to attract and retain qualified instructors and we urgently need to address this problem. The NYSP takes pride in the high quality of its employees. The low salaries make it difficult to recruit and retain qualified staff, many of whom are residents of poverty target areas and can earn more money and work fewer hours as teachers in summer school than as instructors in the NYSP. We need to lift the six-year freeze on salaries. To provide an average increase of just $250 per employee would cost $1.25 million.

We believe it important to continue implementing the Extended NYSP by offering the program at 15 more colleges and universities, which would bring the total to 70, at an estimated cost of $780,000. We also are requesting funds to serve more youngsters in unserved and underserved areas by establishing ten additional summer projects, which would cost approximately $520,000. This summer there will be 141 NYSP projects, one less than in 1978. Although 25 new institutions wanted to participate in the 1990 NYSP, only nine could be funded, for a net increase of only six projects.

Last summer, many projects were forced to turn away hundreds of applicants, because of lack of funding. For example, the projected enrollment for the NYSP project last summer at the University of the District of Columbia, which recruits from areas such as Anacostia, was 425. In fact, over 1,000 youngsters applied to participate. Of those, 575 were enrolled; the remainder could not be accommodated. An increased appropriation would allow existing projects to serve many more youngsters.

In addition, greater resources would enable participating institutions to increase the number of contact days. During the summer program, because of lack of funds, institutions now are operating only 25 days on average, five days fewer than the maximum authorized to be funded by the NYSP guidelines. During the Extended NYSP, projects typically are operating about 20 days, which is the minimum number allowed by the guidelines (30 is the maximum number that can be funded; the current appropriation level, however, does not support 30 days). To add one operating day to the program would cost approximately $312,000 for the summer program and $145,600 for the Extended NYSP.

President Bush recognized the need for constructive alternatives to drug abuse in his 1990 National Drug Control Strategy and said his Administration would support programs that "improve opportunities for young people from drug-ridden neighborhoods to participate in recreational and educational programs outside their immediate environment." The NYSP is precisely the type of program envisioned by the President's anti-drug abuse strategy. The NYSP also helps to address many other problems facing disadvantaged young people. Building on the base of federal support and in partnership with states, localities, and the private sector, the NYSP can help to direct the energies of these youngsters into constructive channels and to create more success stories such as that of Aaron Moore.

For the foregoing reasons, we request that you recommend an FY 1991 appropriation of $14.65 million for the NYSP.

Thank you very much for the opportunity to testify this morning.

Senator **Burdick**. What is the National Youth Sports Program doing to educate young people about alcohol, tobacco, and drug abuse?

Mr. **Moore**. Through my involvement with the National Youth Sports Program, for the first time I had learned that alcohol was also a drug, because most times, because alcohol use is so prevalent in our society and it is accepted, it is legal, it is not seen as being a drug or something that could be abused.

Alcohol or substance abuse is also something that is covered during the enrichment programs. We view video tapes, we have guest lecturers who come in and talk about the harmful effects of alcohol and other drugs.

Senator **Burdick**. Thank you very much.

STATEMENT OF WAYNE SANSTEAD, NORTH DAKOTA SUPERINTENDENT OF PUBLIC INSTRUCTION, ON BEHALF OF THE COUNCIL OF CHIEF STATE SCHOOL OFFICERS

Senator **Burdick**. The next witness is, and I am pleased to introduce, Mr. Wayne Sanstead, North Dakota Superintendent of Public Instruction for the Council of Chief State School Officers. It is a pleasure to introduce to you this gentleman from North Dakota.

Mr. **Sanstead**. Mr. Chairman, it is a privilege to be here. I am delighted to have heard the previous speaker, because certainly he mentioned some relevant aspects of education that I think are most important, especially coming from the Governors' meeting, the NGA meeting, with the president of Charlottesville, and stressing as he did the value of education, and certainly the sixth goal of the national goals on education right now is dealing with drug abuse, your question was most appropriate.

I am pleased to testify on behalf of the Council of Chief State School Officers on education funding for fiscal year 1991. Last evening we had the privilege of having Senator Mitchell with the joint NASBE, National Association of State Boards of Education and Chief State School Officers joint legislative conference. And we are very pleased to see the congressional priorities being delineated for education at this time.

Our council commends you, Mr. Chairman and members of the subcommittee, for your commitment and certainly the high priority that you have placed on education and children's programs, and this hearing is evident of that once again.

We urge you to support the following funding requests which are supported by the committee for full funding for education: a $5 billion increase above baseline, and a $720 million in new outlays for education, a $1 billion growth in budget authority for Head Start—again, a program that deals with the goals of having a youngster ready to attend school is the first goal from the educational summit conference, and $1.8 billion in new budget authority for child care and child care programs, which also speak to those needs.

We recommend these amounts be authorized in the budget resolution, allocated to the subcommittee and appropriated, without reducing current service levels for other vital job training, health, and social service programs under the jurisdiction of this subcommittee.

We support a $1 billion increase over baseline for the chapter 1 compensatory education program for the disadvantaged. Chapter 1 is an essential investment in the education of children in our poorest urban, and I hasten to add, rural areas, which you know only too well, Mr. Chairman, who are most in risk of school failure.

Chapter 1 currently serves only 55 percent of the eligible participants in this country and needs to be targeted as a major Federal effort in the improvement of education.

An additional $1 billion would enable 1 million additional children to be served by the program and would substantially advance us toward the goal of assisting all eligible children by 1993 as outlined in the Hawkins/Stafford Amendments, Elementary and Secondary Education Act Program of 1989.

To assure the effective implementation of the chapter 1 program improvement provisions in Hawkins/Stafford, we urge members of the subcommittee to embrace the President's request of $24 million there for program improvement efforts. This assistance is necessary to assure that State education agencies are able to provide the kind of direct assistance during the 1991-92 school year, to the schools designated as needing improvement. This money is essential to leveraging ongoing, positive change in our chapter 1 programs across the country.

We also request your support for appropriating a full 1 percent of the total chapter 1 grant for administration of the chapter 1 program, as authorized in the Hawkins/Stafford amendments. These funds would enable State and local education agencies to fulfill their responsibilities for program operation, monitoring, evaluation, and general technical assistance.

Since all program improvement funds must be used for direct services to the schools, a full 1 percent is needed to carry out the State responsibilities relative to program improvement, as well as fulfilling existing responsibilities. With a $1 billion increase in chapter 1 over baseline, we calculate the full 1 percent cost, then, for State administration, would be about $66 million.

The council also urges increased funding for chapter 2, the primary, Federal resource program to assist State and local innovations and improvements in education.

Public Law 100-297 provides clear, national priorities now for chapter 2, focusing on the needs of students at risk of school failure, program quality and innovation. States and localities are using their chapter 2 funds for these purposes through staff development, curriculum development and in coordination with a large number of Federal and State initiatives aimed at the effective schools movement and success for students most at risk.

We urge you to appropriate at least $515 million for chapter 2. This increase would insure that funding at current service levels is available to pursue recently authorized initiatives.

For the record, we provide you with a report on State program improvement activities being utilized under chapter 1 and chapter 2.

We also support other programs which provide innovation and quality in education, such as the Dwight D. Eisenhower Mathematics and Science Program.

The council strongly supports requested increases in the programs of educational research and statistics, particularly the National Center for Educational Statistics and the National Assessment of Education Progress. These appropriations are essential to maintain general and needed improvements in our measures of the dimensions, quality, and progress of our schools.

We just listened, Mr. Chairman, to Mr. Porter, special advisor to the President, this morning at a breakfast session on national education goals. I was impressed when he told us we have been on about a 70-month gain period for the improvement of the economy in the Nation. I only wish those same kind of statistics were available for our home States, Senator. We have been certainly in a 70-month downturn, and the fact of the matter is, that if the kind of snow we see out here today were happening in North Dakota where it usually happens, and we have had about an inch all winter, it does indicate, I think, the kind of stress that is placed upon the States in providing adequate resources for some of these educational programs, specifically those addressing the President's national goals and those adopted by the National Governors Association.

So, our council, as the chief State school officers of this Nation, highlight certain critical items in the fiscal year 1991 budget. In the appropriations, it should be noted that the chief State school officers believe that all programs in these appropriations, serving at-risk populations, handicapped, education, bilingual education, certainly our child nutrition programs.

We were distressed last night to hear that one of the President's recommendations was to reduce the child nutrition program funding in order to, of course, increase Head Start funding. But we feel that that would be a very contrary and certainly nonproductive and certainly, for education, a major loss.

PREPARED STATEMENT

So, we hope that the increases that you are considering for inflation, for real growth and educational expenditures for fiscal year 1991 will be a continuing committee priority. These resources are essential to meet the needs of the special populations and certainly create for us an independent, productive national citizenry and a work force to continue the kind of growth that the special assistant to the President spoke to us about today.

Thank you for your time and attention, Mr. Chairman.

[The statement follows:]

STATEMENT OF WAYNE SANSTEAD

Mr. Chairman, I am pleased to testify on behalf of the Council of Chief State School Officers on education funding for fiscal year 1991.

Our Council commends you, Mr. Chairman and members of the Subcommittee, for your commitment to a high priority for education and children's programs in the federal budget. We urge you to support the following funding requests which are supported by the Committee for Education Funding: a $5 billion increase above baseline and $720 million in new outlays for education; a $1 billion growth in budget authority for Head Start and $1.8 billion in new budget authority for child care and early childhood programs. We recommend that these amounts be authorized in the budget resolution, allocated to the Subcommittee and appropriated; without reducing current service levels for other vital job training, health and social service programs under the jurisdiction of the Subcommittee.

We support a $1 billion increase over baseline for the Chapter 1 Compensatory Education program for the disadvantaged. Chapter 1 is an essential investment in the education of children in the poorest urban and rural areas who are most at risk of school failure. Chapter 1 currently serves only about 55 percent of eligible participants. An additional $1 billion would enable over one million additional children to be served by the program and substantially advance us toward the goal of assisting all eligible children by 1993, as outlined in the Hawkins/Stafford Elementary and Secondary Education Act of 1989.

To assure the effective implementation of the Chapter 1 program improvement provisions in Hawkins/Stafford, we urge members of the Subcommittee to embrace the President's request of $24 million for program improvement efforts. This assistance is necessary to assure that state education agencies provide direct assistance during the 1991-92 school year to the schools designated as needing improvement. This money is essential to leverage ongoing positive change in the Chapter 1 program.

We also request your support for appropriating the full 1 percent of total Chapter 1 grant for administration of the Chapter 1 program as authorized in the Hawkins/Stafford Amendments. These funds enable state and local education agencies to fulfilll their responsibilities for program operation, monitoring, evaluation, and general technical assistance. Since all program improvement funds must be used for direct services to schools, a full 1 percent is needed to carry out new state responsibilities related to program improvement as well as fulfill existing responsibilities. With a $1 billion increase in Chapter 1 over baseline, we calculate that the full 1 percent for state administration would be $66 million.

The Council also urges increased funding for chapter 2, the primary federal resource for state and local innovation and improvement in education. Public Law 100-297 provides clear national priorities for Chapter 2, focusing on the needs of students at risk of school failure, program quality, and innovation.

States and localities are using Chapter 2 for these purposes through staff development, curriculum development, and in coordination with a number of federal and state initiatives aimed at effective schools and success for students most at risk. We urge you to appropriate at least $515 million for Chapter 2. This increase would assure that funding at current service levels is available to pursue recently authorized initiatives. For the record we will provide you with a report on state program improvement activities under Chapters 1 and 2.

We also support other programs which provide innovation and quality in education, such as the Dwight D. Eisenhower mathematics and science program.

The Council strongly supports requested increases in the programs of educational research and statistics, particularly the National Center for Educational Statistics [NCES] and the National Assessment of Educational Progress [NAEP]. These appropriations are essential to maintain general and needed improvements in our measures of the dimensions, quality and progress of the schools.

On behalf of CCSSO, I have highlighted certain critical items for fiscal year 1991 appropriations. It should be noted as well that the chief state school officers believe that all programs serving at risk populations—handicapped education, bilingual education, and child nutrition programs—must receive increases for inflation and real growth in fiscal year 1991. These resources are essential to meet the needs of these special populations and create an independent, productive national citizenry and workforce.

Senator BURDICK. Thank you. What is your position on some of the other education programs important to North Dakota and the Midwest, such as impact aid and vocational education?

Mr. SANSTEAD. Mr. Chairman, we are certainly concerned with the continuing appropriations for impact aid programs. As you know, with two large military installations on two of our major school districts, the impact, the loss of any tax revenue from property there is a major consideration for the citizens who live in those two districts. We need that kind of continuing Federal support for the national—the defense programs which are located in the State of North Dakota.

And I would want to add that vocational/technical education is a real priority, and I understand it should be out hopefully, within about 1 week for Senate consideration, because the work force is most important. And, preparing that work force for skills, having the skills and the job requirements necessary to have a productive economy are clearly attached to our vocational and technical programs across the Nation, and particularly in our State.

Senator BURDICK. Thank you very much.

Mr. SANSTEAD. Thank you, Senator.

STATEMENT OF DENHAM HARMAN, EXECUTIVE DIRECTOR, AMERICAN AGING ASSOCIATION

Senator BURDICK. Our next witness will be Dr. Denham Harman of the American Aging Association, National Institute on Aging Research.

Dr. HARMAN. Senator Burdick, my name is Denham Harman. I am executive director of the American Aging Association. I appreciate the opportunity to testify on behalf of the American Aging Association on the need to increase support to the National Institute on Aging for basic biomedical aging research.

Average life expectancy at birth is a rough measure of the healthy, useful lifespan, that is, a functional lifespan. Better nutrition, medical care, public health facilities and accident prevention, help to increase life expectancy from 47.2 years in 1900 to 69.2 years in the mid-1950's, then more slowly to 74.9 years today.

Conventional efforts to further increase average life expectancy are now almost futile. The chance of death at any given age decreases toward a limiting value as average life expectancy increases. We have now, almost reached these limits. Today, only two to three of our population die before age 28. For the rest, the chance of death increases progressively with age, in accordance with an inner destructive process, which we call aging. This ensures that few reach 100 years and none live beyond about 115 years, even in the absence of overt disease and under the best of living conditions.

The aging process is now the major risk factor for disease and death after age 28 and limits average life expectancy at birth to less than about 85 years. These facts are obscured by the protean nature of its contributions to nonspecific change and disease pathogenesis, for example, cancer, atherosclerosis, and Alzheimer's disease.

As recognized risk factors for disease are minimized the chance of death decreases toward that determined by the aging process. The functional lifespan could be significantly increased by slowing the rate of damage production by the aging process. Many theories have been advanced to account for this process. For example, the effects of aging have been attributed to molecular cross-linking, changes in the body's immunological functions, damage by free radical reactions, and to senescence genes in our DNA.

Unfortunately, the importance of the aging process to our health and well-being is being overlooked, perhaps because of a belief that our past successes and increase in human lifespan will continue indefinitely.

Funding for basic biomedical aging research is meager. Only between $25 million and $50 million is available per year, largely from the National Institute on Aging. The importance to individuals and to society of further increase in the functional lifespan mandates a major national program to determine the cause of the aging process and the practical means of slowing the rate of damage caused by this basic biologic process.

PREPARED STATEMENT

As a start, we recommend that $100 million by included for this purpose in our next budget for the National Institute on Aging.

Thank you.

[The statement follows:]

STATEMENT OF DENHAM HARMAN

Chairman Harkin and distinguished members of the subcommittee, my name is Denham Harman. I am Executive Director of the American Aging Association [AGE].

I appreciate the opportunity to testify on behalf of the American Aging Association on the need to increase support of the National Institute on Aging for basic biomedical aging research.

Average life expectancy at birth is a rough measure of the healthy, useful life span, i.e., the functional life span. Better nutrition, medical care, public health facilities, and accident prevention helped to increase life expectancy from 47.9 years in 1900 to 69.2 years in the mid-1950's, and then, more slowly, to 74.9 years in 1989. Conventional efforts to further increase average life expectancy are now almost futile. The chance of death at any given age decreases toward a limiting value as average life expectancy increases. We have now almost reached these limits. Today only 2 to 3 percent of our population die before age 28. For the rest, the chance of death increases progressively with age in accordance with an inner destructive process, called aging, which ensures that few reach 100 years and none live beyond about 115 years, even in the absence of overt disease and under the best of living conditions.

The aging process is now the major risk factor for disease and death after age 28 and limits average life expectancy at birth to less than about 85 years. These facts are obscured by the protean nature of its contributions to nonspecific change and to disease pathogenesis, i.e., cancer, atherosclerosis, and Alzheimer's disease. As recognized, "risk factors" for diseases are minimized the chance of death decreases toward that determined by the aging process.

The functional life span could be significantly increased by slowing the rate of damage production by the aging process. Many theories have been advanced to account for the process. For example, the effects of aging have been attributed to molecular cross-linking, changes in the body's immunologic functions, damage by free radical reactions and to senescence genes in our DNA.

Unfortunately, the importance of the aging process to our health and well-being is being overlooked, perhaps because of a belief that our past successes in increasing the human life span will continue indefinitely. Funding for basic biomedical research on aging is meager. Only between $25 million and $50 million is available per year, largely for the National Institute on Aging.

The importance to individuals and to society of further increasing the functional life span mandates a major national program to determine the cause of the aging process and the practical means of slowing the rate of damage caused by this basic biological process. As a start, we recommend that $100 million be included for this purpose in the next budget for the National Institute on Aging.

Senator **Burdick**. Thank you. You have spoken about funding for basic biomedical research. Do you think there is a good balance at NIH between basic and applied research?

Dr. **Harman**. I am talking specifically about targeting money to the aging process itself. This is the process that kills us. Diseases are—if we eliminate all the diseases completely, we would still die. In fact, as a matter of fact, if you eliminated all the causes of cancer completely, you would gain about 2 years in your average life expectancy. Today, as I mentioned a moment ago, it is almost 75 years. If you eliminate all cardiovascular disease, statisticians calculate it is about 5 to 6 years. It is the aging process which is built into us that is killing us. And this is what we are not really tackling. Only a relatively small amount of money goes directly to this purpose, and that is what I am advocating, that more money be placed on this basic process.

Shortly after the National Institute on Aging was formed, Congressmen Tim Carter and Paul Rodgers, who were instrumental in introducing the bill in the House, were asked, what did they think the major emphasis should be in the National Institute on Aging, because it has a broad mandate, and they felt that the major emphasis should be on the process of aging, and I think that this is where we need more money and more research. Thank you.

Senator **Burdick**. Thank you.

STATEMENT OF PATRICIA ALLEN, MINNESOTA STATE BOARD OF EDUCATION ON BEHALF OF THE NATIONAL ASSOCIATION OF STATE BOARDS OF EDUCATION

Senator **Burdick**. The next witness is Patricia Allen, Minnesota State Board of Education, National Association of State Boards of Education.

Welcome to the committee.

Ms. **Allen**. Senator Burdick, my name is Patricia Allen. I am a member of the Minnesota State Board of Education, and I am the chairman of the Governmental Affairs Committee of the National Association of State Boards of Education. NASBE is our name. I am very pleased to have this opportunity to testify.

NASBE's first priority is a substantial increase in funding for chapter 1. Chapter 1 was created 25 years ago through the historic Elementary and Secondary Education Act of 1965. Lawmakers knew even 25 years ago that disadvantaged children would benefit greatly from additional remedial instruction.

Nevertheless, 25 years later, this highly effective program only serves about one-half of the Nation's eligible children.

NASBE also places a high priority on the chapter 2 basic State grant program. My own State of Minnesota uses chapter 2 funds to purchase instructional materials and for teacher training programs.

NASBE also recommends increased funding for early intervention programs. While education programs are essential to the growth and development of our children, early intervention programs provide basic services that address other special needs. We hope the subcommittee will provide enough funding to fully support the child care initiative in fiscal year 1991. Comprehensive, early childhood development programs have demonstrated extraordinary returns for young children and society, and quality child care reaps benefits many times over for children, parents, and employers.

Further, we recommend that the subcommittee provide full funding for the comprehensive, early childhood development centers and the Even Start Literacy Program. We also recommend that the subcommittee provide a substantial increase in appropriations for Head Start.

NASBE would stress one last funding priority: funds for the National Assessment of Educational Progress. Most widely used standardized tests do not adequately measure higher order thinking skills. NAEP is being further developed to assess this kind of learning. Our Nation's education system is, I am sorry to say, doomed to failure if our students are not mastering higher-level and creative thinking skills.

PREPARED STATEMENT

I will close by saying, while many point to the Federal budget deficit and say that the Federal Government simply cannot afford to fund all of these programs affecting children, the issue is not whether our Nation can afford these programs, but whether we choose to afford them. It is our hope that Congress will find within itself the political will to effect budget reform, to more effectively reduce the deficit so that taxpayer dollars can be used for the host of urgent needs that face our Nation.

NASBE thanks you again for this opportunity to testify.

[The statement follows:]

STATEMENT OF PATRICIA ALLEN

Chairman Harkin and distinguished members of the subcommittee: my name is Patricia Allen. I am a member of the Minnesota State Board of Education and I am the chairman of the Governmental Affairs Committee of the National Association of State Boards of Education [NASBE]. I am very pleased to have the opportunity to testify this morning before the Senate Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies on behalf of State board members across the country.

Mr. Chairman, we at NASBE applaud the concern you have demonstrated for education and other programs that serve our Nation's children. We particularly appreciate the fact that you highlighted the President's education budget in a recent hearing and pointed out why it does not meet the President's pledge of making education a top priority for the Nation.

Our first priority is increased funding for chapter 1. As you know, chapter 1 was created 25 years ago through the historic Elementary and Secondary Education Act of 1965. This year, schools across the country will participate in a celebration of that act. It is laudable to think that lawmakers knew even 25 years ago, that disadvantaged children would benefit from additional remedial instruction. But despite that fact, after 25 years the program only serves about half of the Nation's eligible children.

The effectiveness of chapter 1 is well documented. Studies conducted at the Federal, State, and local level show that low-achieving children who participate in chapter 1 do significantly better academically than similar children who do not participate. Chapter 1 is particularly important because of its emphasis on improving remedial education. A recent report documented that those young adults, who by age 18 have the weakest basic skills, are much more likely to drop out of school and be jobless in subsequent years than those with above-average skills.

State board members recommend that the Congress begin paying for education once, by fully funding programs such as chapter 1. What happens instead is that taxpayers end up paying for education three times—first through our public schools, then remedial education programs, and finally public and private basic skill training programs.

NASBE also places high priority on the chapter 2 basic State grant program. Few members of Congress may appreciate how valuable this program is in helping States provide innovative programs and in helping States achieve overall improvement in the Nation's schools.

In my own State of Minnesota, the majority of chapter 2 funds are used for a number of valuable goals—toward the purchase of library materials, audio visual equipment and encyclopedias, funds are also used to buy computers for computer-supported instruction, for staff development, and to provide instructors for gifted and talented students programs.

School districts throughout my State benefit from the program because it enables them to address their own needs and priorities. I am aware that the chapter 2 program does not have support from Congress because of its flexible uses and a perceived lack of accountability. However, Minnesota is working in collaboration with the Federal Department of Education on an effective assessment model for this program. However, we hope that you will not wait until that model is developed to increase funding for the chapter 2 program.

Although education programs are essential to the growth and development of our children and to he well-being of our society, we don't believe that it is wise to choose between funding for programs that educate our children and those which provide our children with other basic services addressing their special needs. Congress must make a commitment to the whole child. NASBE believes that there is no one single program or method that can single-handedly address children's multiple educational and developmental needs. Therefore our next recommendations are for support of a variety of early intervention programs.

We hope the subcommittee will reseve funds in its appropriations bill for the child care initiative. It seems very likely that Congress will pass a comprehensive child care bill this year. We urge your committee to provide the necessary level of funding to fully fund the child care initiative in fiscal year 1991. Comprehensive early childhood development programs have demonstrated extraordinary returns for young children and society, and quality child care reaps benefits many times over for children, parents, and employers.

Further, we recommend that the subcommittee provide full funding for the comprehensive early childhood development centers authorized under the Hawkins-Stafford amendments of 1988. The purpose of the centers is to provide early and comprehensive services to disadvantaged mothers, infants, and toddlers. While this is a demonstration project, the exploratory work of these funded projects show to the educational community by demonstrating the most effective types of comprehensive early intervention efforts. These comprehensive programs can reduce the numbers of dropouts, lower teenage pregnancy rates, and decrease dependency on our welfare system.

NASBE would also recommend that the subcommittee provide adequate funding for the Even Start Literacy Program, also created as part of the Hawkins-Stafford amendments and reauthorized in the Senate's literacy initiative. Even Start integrates early childhood education and adult education for parents. The funds are used to operate family-centered education programs which involve parents and children in a cooperative effort to help parents become full partners in the education of their children. The benefits of parental involvement in their children's education is also widely documented and further underscores the importance of family.

We also recommend that the subcommittee provide a substantial increase in appropriations for the Head Start Program. This program currently serves less than 20 percent of eligible children. Yet, this much recognized and sparingly funded program gives disadvantaged children the preparation they need to succeed in their traditional schooing.

NASBE would stress one last funding priority—more funds for educational research and assessment. We recommend that the subcommittee increase funding for the national assessment of educational progress. NAEP is working toward the development of assessment techniques to measure the outcomes of the national educational goals adopted by the President and the Governors.

While schools are being pressured to teach higher order thinking skills—such as the ability to analyze, reason, and apply knowledge in creative, problem-solving ways, the standardized tests widely used to assess this knowledge not only fail to measure the knowledge but may actually impede its development. Many educators believe that test outcomes have become so critically important to schools and administrators whose performances and reputations are rated by the rankings of their students. And considering the high-stakes nature of testing, teachers may be encouraged to tailor curriculum to the contest of those tests.

State boaard members want students to be able to do far more than just restate facts they've been taught. NASBE believes our goal must be to teach students to think and to analyze using the information they have been taught. We are doomed to fall short of this goal if we are unable to monitor development and measure student mastery of the thinking skills we seek to impart.

While NASBE believes that full funding for effective education programs is critical, we would be less than candid if we did not say that in addition, we believe our entire system of public education must be rewarded as well. Federal, State and local governments can provide the best education programs in the world to our young people and it won't make a difference if our children are hungry, sick, abused or homeless. Our best teachers are ineffective if the basic needs of the children they are trying to teach are not being met or if the special problems confronting our youth are unaddressed. Schools must also address the needs of the whole child.

I will close by saying there are many who point to the Federal budget deficit and say that the Federal Government simply cannot afford to fund all these programs affecting children. The issue is not whether our Nation can afford these programs but whether we choose to afford them. The very existence of our massive deficit is the result of past choices regarding taxes and Federal spending.

When we ask for increases for these programs, we understand that you and the entire Appropriations Committee are restrained by the Federal deficit and the enormous amount of money paid toward the interest on the debt. We hope that Congress will find within itself, the political will to effect budget reform to more effectively reduce the deficit so that taxpayer dollars can be used for the host of urgent needs that face our Nation. NASBE stands ready to work with you. Thank you for this opportunity to testify.

Senator Burdick. Thank you. The administration budget proposal, again, calling on the States to assume more of the burden of financing public education. As you know, the total budget proposal for education is only a 2-percent increase. My question is this. What can we really expect the States to do in regard to education funding, and what is the role of the State boards of education in this effort?

Ms. Allen. Unfortunately, the role of the State boards of education in many States is to hold the hands of local districts as we try to figure out how to survive deficits, because unfortunately, any cut of Federal spending is directly felt at the local district level, and it is also felt in the State departments of education across the country, because we are less capable of serving and providing for special needs at the local level.

One of the major functions of State boards of education and State departments of education is to provide technical assistance. And with the calls from the President and the Congress to restructure our educational system, we are caught in the unhappy circumstance of having to continue to provide the kind of educational programming that we have been providing at the same time that we are being asked to redesign and restructure our system. I am sorry, but we do need money to do that.

Senator **BURDICK**. Thank you.

Ms. **ALLEN**. Thank you.

STATEMENT OF MEG POWER, COCHAIR, NATIONAL LOW INCOME HOME ENERGY ASSISTANCE COALITION

Senator **BURDICK**. Dr. Meg Power, cochair, Low Income Home Energy Assistance Coalition.

Dr. **POWER**. Thank you, Mr. Chairman.

I am Meg Power. I am chair or cochair of the National Low Income Energy Assistance Coalition, which is a group of over 40 public, nonprofit, advocacy, and private groups who are interested in strengthening the low-income home energy assistance programs.

Our membership ranges from the National Community Action Foundation and the Council on Senior Citizens to Con-Edison and the Pacific Gas Corp. and the Governor of Iowa's office.

We have come today to urge you to reverse the trend of decline in the Low-Income Home Energy Assistance Program and to fund it at a much more adequate and appropriate level of close to $2 billion.

You have a lot of material from the administration which claims to provide a basis for a very large cut in this program. They allege that there is little need for help for energy cost among the poor anymore and that what needs there are can be met from some other source.

In fact, these are patently false and our written testimony addresses every single point they have made with statistical material showing that the need is there and that alternative resources are not there. In fact, these statistics come mainly from the Department of Health and Human Services itself.

The fact is, that the cuts over the past 3 years have been too deep and the program is nowhere near as large as it needs to be right now. The benefits are too low, and 70 percent of the eligible households are not being served. Nationwide, over 900,000 households, that is 2.7 million people, have been dropped from this program since 1987.

In North Dakota, the drop in households is a little smaller, about 5 percent of your households have dropped out, but the benefit cut is comparable to the national benefit cut. Benefits were down 15 percent by 1989. Fuel costs are not down 15 percent.

The results of this are is that thousands of people do not have all the benefits they need. In a cold winter like this one, many, many households used up all of their benefits by January and they faced February and March on their own resources, and very often they just did not have the cash to pay for the energy in those months, and they remained cold.

HHS, itself, reported that in 1987, which was a pretty mild winter, 500,000 households who were LIHEAP eligible, spent more than 2 weeks on average, in winter without any heat, because they could not afford it. People whose heat and lights are off face homelessness. Landlords may evict people who do not pay their heat bills or their light bills.

In Iowa in the Cedar Rapid shelter at Christmas time, there were 96 households, and a survey showed that one-half of them were in that shelter because of something related to their energy costs. Either, No. 1, they could not pay their bill and got evicted or, No. 2, the heating equipment was broken, even in their own homes, and they could not pay to have it fixed and they were frozen out in the middle of the coldest December that Iowa remembers.

PREPARED STATEMENT

There have been more drastic consequences, even than homelessness. People, elderly people, froze to death in their own beds in Detroit and in St. Louis this winter, an effect we hoped would never happen. And there have been dozens, possibly hundreds of fires in inner cities in homes where there was no-conventional heat source. Six children died in such fires in homes with no heat in Philadelphia in the past 2 weeks, alone.

Mr. Chairman, we urge you to put this program back at a more reasonable level to meet the need. Thank you very much.

[The statement follows:]

STATEMENT OF MEG POWER

My name is Meg Power, and I am a Co-Chair of the National Low Income Home Energy Assistance Coalition, an ad hoc group of over 30 public -private sector members. The other co-chairs are the American Association of Retired Persons, The Citizens Labor Energy Coalition and the National Consumer Law Center. While the Coalition member organizations support different levels of funding for the LIHEAP block grant, most of them in the $2 billion range, we are unanimous in agreeing that significant increases above current levels are required and that the three year trend of reductions must be reversed.

Mr. Chairman, the Administration's Budget Request documentation repeats the specious arguments used in past years seeks to show that the poor do not need energy aid and that non-federal aid is adequate to their remaining need. Let me briefly refute these:

The first claim is: indexed entitlements have "caught up" with fuel prices. Of course, benefits are not indexed. In fact, on the average, they are 38% lower than in 1970 (CRS 1989). The National Consumer Law Center reported in 1989 that home energy costs exceed 25% of AFDC income in 41 states. For Social Security recipients, if income indexing has lifted them over the eligibility level for LIHEAP, then they are no longer one of those desperately poor households who qualify. At least 8% of LIHEAP eligible households are not receiving any indexed entitlements (U.S. Census, 1984).

The second claim is that benefits in other programs cover home energy costs. However, in the initial program eligibility determination, these benefits are generally counted as income (with the exception of Food Stamps); States are not required to serve households not vulnerable to energy bills.

The Budget document cites the availability of AFDC Emergency Assistance as an alternative. In response, the American Public Welfare Association is preparing a study for the Subcommittee which will be available shortly. It will show that in the 10 states which allow these funds to be used for energy among 20 other purposes, AFDC/EA is not a viable replacement for LIHEAP benefits. In all 31 states operating AFDC/EA programs, $256 million was available in FY 1983.

A third claim is that fuel prices have moderated. In fact Mr. Chairman, HHS provided data to this Subcommittee last year showing low income energy expenditures 2% higher for 1989 than 1987 when LIHEAP funding was 32% higher. Of course, this past winter's bitter cold and price increases will bring expenditures far above last year's.

And finally, the Administrative reiterates that oil overcharge funds are available as a substitute, citing $179 million in undesignated funds in the states, a figure considerably higher than the National Consumer Law Center Report to DOE. Setting aside the fact that only a few states have these undesignated funds, proposed cuts in the HHS and DOE low income energy program budgets both cite the availability of these same funds. However, the combined cuts in two departments total $465 million. In fact, cumulative cuts from FY 1986 LIHEAP levels total $1.91 billion to date, but only $660 million of PVE funding has been available to compensate.

The truth is that low income households are poorer now, while their shelter costs, including energy are higher. It is obvious to all of us concerned about low income housing that existing programs to support income and to maintain shelter are inadequate.

The Center on Budget and Policy Priorities 1989 study shows that the majority of poor renters, typical-LIHEAP eligible households, paid over 65% of total income for rent and utilities.

But LIHEAP benefits are not the equivalent of housing subsidies. Nearly all low income households face prohibitive housing costs but not all are equally affected by energy costs. LIHEAP programs target those with the highest energy costs in relation to income and give them additional benefits.

Leaving aside its deceptive misuse of statistics, HHS also reports the following about LIHEAP households:

- In 1989 they spent 13.8% of household income on home energy, up from 13.2% in 1987.
- Their average income was under $7000 a year.
- Their incomes increased 1.7% from 1988 to 1989 while the average U.S. household income rose 4.5%, inflation was over 4%.

Mr. Chairman the LIHEAP cuts of the last few years have meant extreme hardship to the LIHEAP eligible population. Only about 30% now receive help. The statistics show that 900,000 households or 2.7 million people were dropped from the program from FY 1987 to FY 1989. Benefits in 1989 were 8% below 1987 and 20% below 1985. In Iowa natural gas users receive $80 a winter, whereas in 1983 the same client would have received $385.

A forthcoming GAO report will describe in greater detail how States reduced eligibility, cut benefits and even limited physical access to the program by reducing the months of operation and the number of sites to where help is provided.

In a fiercely cold period, the program has no margin to respond to extraordinary need. Many states reported to us that countless households had exhausted all available benefits by January and have to depend on their own resources through the summer.

But we already knew that millions cannot pay for energy from their own pockets. HHS presented figures collected in 1987, an unsually mild year, and they showed nearly half a million LIHEAP eligible households spent an average of 18 days in winter without heat because of ineligibility to pay bills.

Mr. Chairman, living without utilities is a prescription for homelessness and very possibly a death sentence.

In Cedar Rapids, Iowa alone a survey of 96 homeless families in eight weeks of this winter showed that 48 of them lost their homes as a result of inability to pay either for fuel or for repair of their heating systems. Most had little hope of getting the large sums necessary to pay overdue arrearages that would permit utility reconnection in a new home.

The public debate has often touched on the possible loss of life due to hypothermia and, indeed, elderly persons did freeze to death in their own homes in St. Louis and Detroit this winter. But fire in the houses of those with no utilities is a far more vicious and frequent killer. On March 1, Philadelphia lost 13 year old Lamont Peacock and his 10 and 8 year old brothers Melvin and Tyrail—good students, beloved by the elderly neighbors for whomthey did chores. The space heater that was replacing the gas heat they lost over a year ago engulfed their room in flames.

This same tragedy has been repeated in most of America's major cities: children knock over candles or kerosene heaters in homes without power; electric heaters explode; charcoal fires lit in desperation asphixiate the residents. Not dozens, but hundreds of children are now lost.

Until the Energy Assistance program is funded so it can both increase its caseload and provide the larger sums necessary to reconnect families now living in the dark, this carnage will continue.

Mr. Chairman, the Administration has termed this program a "low return" program along with several other income maintenance programs. One wonders about their economics: is it low return because the funds invested in keeping an elderly person warm do not pay back in taxes collected or avoided health care costs? Is it lower payback to keep a low income child housed and warm than in day care? How about the low income child with disabilities who, if she survives childhood, has some probability of costing the government money? As these funds are cut to fund badly needed Head Start services, we must question the logic - what danger does the child go home to? what does he face when he is six?

On behalf of the many public and private sector orgniztions in our Coalition, I urge you to reverse the trend of the past three years and increase LIHEAP funding.

Senator BURDICK. Thank you. We have a lot of sales out there called two-fers, that is a two-for-one discount for buying in bulk, for example. What do you think we can do to encourage companies or States to offer discounts on fuel for the LIHEAP Program?

Dr. POWER. I think a great deal could be done with that. Some States have been very innovative on their own, and have gotten big discounts. The Government is buying over $1 billion of natural gas and fuel oil every single year, and that probably makes them the single largest residential customer in America. That is about 1 percent of the $100 billion that we spend. The LIHEAP Program ought to be treated like a wholesale customer and get the kind of discounts that they deserve. There ought to be a fund set aside that the Department of Health and Human Services gives out as an incentive to those States and get big discounts on their energy costs.

Senator BURDICK. That is very intriguing. You treat these people like wholesale customers.

Dr. POWER. Absolutely. Because it is not the actual purchaser, it is the State that is buying for many, many people at one time.

Senator BURDICK. Thank you very much.

Dr. POWER. Thank you, Mr. Chairman.

STATEMENT OF DON BOLCE, DIRECTOR OF INFORMATION SERVICES, NATIONAL HEAD START ASSOCIATION

Senator **Burdick**. The next witness is Don Bolce, director of information services, National Head Start Association. Welcome to the committee.

Mr. **Bolce**. Mr. Chairman, thank you for the opportunity to come before you.

Twenty-five years ago, about this time, there were a group of committed individuals and far-reaching thinkers who were planning a program for low-income children. That program was Head Start, and in the summer of 1965, it served 560,000 children. Today, in 1990, Head Start is well known as a very successful program for low-income children. It served more than 12 million low-income children and their families since its beginning.

However, since 1965, Head Start still only reaches one out of five eligible children. The sad fact is most low-income, preschool children cannot participate in Head Start because there is no space for them.

This year, Congress is considering Head Start's reauthorization, amidst a lot of encouragement to fully fund their program to reach every eligible child. Senator Dodd and Senator Kennedy have introduced a reauthorization bill for Head Start called the Head Start Expansion and Quality Improvement Act which would fully fund Head Start by 1994. The proposal would also include some provisions which would strengthen the quality of Head Start.

With this in mind, we are asking you for a $2.7 billion appropriation in 1991. This is within the appropriations levels included in that proposal. Our goals with this proposal are twofold: to increase the services to Head Start and also, to strengthen and maintain program quality.

The first goal is expansion. In your own State, in North Dakota, Head Start serves only 710 children. Minot public schools was only able to serve 100 children. In Grand Fork, only 60 children. The communities of Garrison, Grafton, Valley City, do not have any Head Start at all. With this expansion, we will be able to reach these additional communities.

The other thing we are looking to do in Head Start is to insure that programs have sufficient funds to operate high quality programs, and the reauthorization proposal includes that.

The Head Start programs have been seriously underfunded for years. The most shocking examples of that is in the salaries of Head Start; 47 percent of the Head Start teachers in the country in 1988 had salaries under $10,000 a year. In Iowa—in Davenport, IA, Head Start teachers start at $6,800 a year, and their top salary is only $8,800 a year, regardless of the number of years they have worked there.

PREPARED STATEMENT

This appropriation of $2.7 billion in 1991 would allow us to make a serious commitment toward reaching full enrollment by 1994. We could add 295,000 children. We could also ensure that that expansion is not provided at the cost of high quality services for those children.

This committee has supported Head Start before. We look for your support in 1991. Thank you.

Senator BURDICK. If your recommendation is carried out and made law, how much of the increase would be increase in number of school children versus increase in teachers' salaries?

Mr. BOLCE. Under the provisions of the reauthorization bill, 5 percent of the total appropriation could be reserved for Head Start salaries, for improvements in Head Start salaries. So, I could not tell you the percentage of the increase, but certainly, it would be 95 percent of the money would go for either expansion or continued services.

Senator BURDICK. Thank you.

[The statement follows:]

STATEMENT OF DON BOLCE

In 1965 a group of visionaries came together to create Project Head Start to ensure that low-income preschool children would have a fair chance for school success and healthy, productive lives. With its comprehensive, interdisciplinary approach and its commitment to family and community involvement, the Head Start model has proven itself over the past twenty-five years as our nation's best hope of helping low-income preschool children overcome the many obstacles of poverty confronting them before they enter formal education.

Since its dramatic beginning in the summer of 1965, nearly 12 million economically disadvantaged preschool children and their families have benefited from Head Start's preschool education, parent involvement, and health and social services. Today, nearly 1,900 Head Start programs across the country provide these services in more than 2,000 counties to over 450,000 children. Head Start is a proven success with broad bipartisan support. And yet, even with its record of success, after twenty-five years only 20% of all children eligible by law can participate in the program.

There is widespread support for fully funding Head Start. The National Governors Association and the White House have established a national goal of ensuring that every child is ready for school. Recognizing the need for an educated workforce in the twenty-first century, the Committee on Economic Development has called for fully funding Head Start over the next four years. In their call for full funding for Head Start, former Presidents Ford and Carter declared "spending money for these young Americans is not wasteful; it is wasteful not to invest."

The National Head Start Association believes that the time has come to fulfill the promise of Head Start, and provide all children in need with the opportunity to benefit from the program. We urge the nation and this committee to take a significant step towards the goal of adequately funding Head Start to provide high quality, comprehensive services to all children who need these services by 1994.

With this goal in mind, we encourage a 1991 appropriation of $2.7 billion an increase of $1.314 billion over the current funding levels. This in keeping with the level that would be authorized by the "Head Start Expansion and Quality Improvement Act of 1990," S. 2229, introduced by Senator Kennedy and Senator Dodd. The increased funds would be used to strengthen and support program quality and to significantly increase the number of children who can benefit from the program.

The National Head Start Head Start Association believes strongly in the dual goals of supporting program quality and increasing enrollment. For this reason, NHSA supports the concept of a quality reserve or "earmark" that would require that a portion of new funds be used to ensure that programs have sufficient resources to provide quality services to children already enrolled. Such an earmark is necessary because of a continuing policy in Head Start of inadequate funding on a cost-per-child basis.

For more than a decade, local Head Start resources have been stretched by inflation and a policy to serve the greatest number of children at the lowest costs. An recent analysis by the High/Scope Educational Research Foundation revealed that "from 1981 to 1989 per-child spending, which is largely determined by staff salaries and benefits, declined 13% in real dollars." This decline in spending on a per-child basis threatens to erode program quality.

Head Start Cost Per Child, 1981-89

Year	Cost Per Child	% Change	Price Deflator*	Cost per child in 1989 $	% Change
1981	2,134		69.2	3,084	
1982	2,203	3	74.1	2,973	-4
1983	2,231	1	77.6	2,875	-3
1984	2,229	0	81.4	2,738	-5
1985	2,339	0	85.1	2,749	0
1986	2,248	-4	87.6	2,566	-7
1987	2,469	10	91.3	2,704	5
1988	2,623	6	95.4	2,749	2
1989	2,762	2	100	2,672	-3
Overall		25			-13

*Implicit price deflator for state and local government purchases; 1989=100.
Source - High/Scope Educational Research Foundation, 3/90

The most shocking indicator of this decline in cost-per-child funding is the low salaries of Head Start staff. A 1988 salary study conducted by DHHS/ACYF revealed that 47% of Head Start teachers earned salaries of $10,000 per year or less. Head Start salaries have always been low, but today many programs report serious problems in recruiting and retaining qualified staff. In many cases, dedicated Head Start staff are forced to choose between remaining with Head Start or changing jobs in order to financially support their own families. Appropriately trained, qualified staff are essential for the delivery of high quality Head Start services. When Head Start programs are denied the funds to pay such staff, their ability to provide high quality services is threatened.

Inadequate funding on a cost-per-child basis threatens other areas of the program. Limited funding has forced some programs to reduce the number of health and social service staff, a traditional strength of the program. Indeed, in spite an ACYF Social Service Task Force Report which recommended family caseloads of no greater than 35 for each social service worker, an ACYF study revealed that limited funding forced more than 70% of Head Start grantees to maintain caseloads higher than 60 families for every worker. In other instances, limited funding forces Head Start program to operate in inadequate or run, run-down facilities, to cut back on transportation services or reduce hours or days of operation. For all of these reasons, additional funding for existing program services is essential to maintain the quality of the Head Start program.

Our second goal is expand Head Start services to all eligible children who need them. The children who participate in Head Start today are scheduled to graduate from high school and become productive members of American society in the twenty-first century. We know that participation in a quality Head Start program increases the likelyhood that these Head Start children will indeed stay in school and become productive citizens. But after twenty-five years, most children eligible for Head Start still cannot participate because there is no space for them. The sad fact is that most low-income preschool children and their families today do not have access to Head Start's comprehensive early childhood education, health, social services and parent involvement.

A 1991 appropriation of $2.7 billion dollars can ensure high quality Head Start services to an additional 295,000 children next year. This would mean that an additional 295,000 economically disadvantaged young children would have the benefits of preschool education, health services, and family support that would increase their likelyhood of graduating from high school in 2004, of leading healthy lives and contributing to society.

Mr. Chairman, and distinguished members, the National Head Start Association requests that this Appropriations Subcommittee make a commitment to fulfilling the vision of Head Start, and a commitment to an additional 295,000 economically disadvantaged preschool children in 1991, with an appropriation of $2.7 billion, the full amount authorized by Senator Dodd and Kennedy's legislation. We thank the committee for its many years of support for Head Start and look forward to your continued support.

STATEMENT OF DAVID BRADLEY, NATIONAL COMMUNITY ACTION FOUNDATION

Senator **Burdick**. The next witness is David Bradley. Welcome to the committee.

Mr. **Bradley**. Thank you, Mr. Chairman. I am David Bradley and I want to spend just a couple of minutes talking about funding for the community services block grant.

The administration, is again, recommending zeroing out the program. It is no surprise. It is a continuation of the budget proposals by the previous administration, the Reagan administration. The arguments that they have come up against the program are arguments that we have heard in the past, arguments that have been rejected by GAO, been rejected by HHS-funded studies, and have been rejected by both House and Senate authorizing committees, so there really is no new arguments that the administration is putting forward.

I would like to point out a couple of things about the community services block grant. First of all, it is unique. It provides some very unique services in the States that are unduplicated. I just happened to pick three States, Oregon, Iowa, and North Dakota, that I will put out a couple of examples.

One is in Oregon, 1988, 1989, serious drought, 10,000 migrant and seasonal farm workers were stranded in Oregon. They had come for a harvest and there was not anything to harvest. They were stranded without money, without transportation, without health, without food, and with inadequate housing.

The Oregon community action agencies took the lead in terms of providing services and emergency services to that community. They were the focal point of that crisis. Over 13,000 individuals received help because of community action agencies. The State of Oregon eventually appropriated $500,000 to help relieve the crisis, but the fact is, the community action agencies, with their community services block grant funds, were there and were able to respond.

Iowa, Farmstead Foods in Cedar Rapids. It is a meat packing plant, just closed, early March; 2,000 jobs were lost. Workers received less than 2 weeks' notice before the plant closed. Health insurance coverage was terminated, and the company did not have sufficient assets to meet its final payrolls.

While the workers were still reeling from the sudden shock of losing their job, the local community action agency, with community services block grant funds, stepped in. They provided food, weekly food boxes, arranged with the State of Iowa for a 2-month extension of LIHEAP, coordinated community general assistance funds and coordinated other voluntary services. Without that community action agency, they would have been in a much more serious crisis.

North Dakota, 100 percent of North Dakota, the entire State is served by seven community action agencies. Your State currently receives about $830,000 in CSBG funds.

In 1987, we funded—Congress funded a Demonstration Partnership Program, and North Dakota received one of the first grants, and there were five grants made in that initial year. In fact, it was a Proxmire amendment that got the $1 million into the program.

That is a program that deals with self-reliance and getting the low income off of welfare and making them more self-sufficient.

The programs worked. The State is now putting in money, other communities are putting in money, and North Dakota is a shining example of why CSBG dollars are unique.

So, I end with a couple of things. One is that the Bush budget proposal is going to be rejected this year. Both House and Senate Budget Committees are going to come out very strong on community services block grant.

Second, we are going to be reauthorized. Both House and Senate, in a bipartisan fashion, will pass a community services block grant reauthorization bill, and I might add that it will include more funding for the small States, which has been a concern of yours. The minimum funding for small States will be addressed, and I think it will be addressed to your satisfaction.

And finally, authorization oversight will, again, reject the administration's argument.

PREPARED STATEMENT

So, I leave you with this final thought. In my office, there is a picture of Lyndon Johnson signing in the Economic Opportunity Act on August 20, 1964, and I notice that Hubert Humphrey's sister, Frances Howard, is in the audience. Hubert Humphrey is up there, but so are you, Senator, and you were there when this Nation made a commitment to fighting the war on poverty. The fact is, community action agencies are still there, they are still carrying on the commitment and they deserve some support from this committee.

Thank you very much.

[The statement follows:]

STATEMENT OF DAVID BRADLEY

My name is David Bradley. I am here today on behalf of the National Community Action Foundation, which is the Washington representative of the nation's 900 Community Action Agencies. Mr. Chairman, I am grateful for this opportunity to testify before this Subcommittee.

The Bush Administration has requested the elimination of the Community Services Block Grant (CSBG). This is not the first time an Administration has made such a request.

In the Reagan years, the Administration argued that the gap caused by the removal of CSBG monies could be filled by other funds, such as the Social Services Block Grant, Head Start, Low-Income Energy Programs, Community Development, and Job Training. However, as the Subcommittee is aware and, I might add, as most communities are aware, tremendous pressures exist to cut out or to reduce funding for most of those programs as well.

On behalf of the Community Action Agencies, we request that you consider the following points:

- The GAO told us in 1986 that Community Services Block Grant funds are used for unique and non-duplicative purposes.
- CSBG funds are used to initiate new local programs and to provide direct services not already available.
- The HHS-funded report on FY1987 CSBG showed that these monies fund the local distribution and coordination of approximately $3 billion in federal, state, and private funds.
- The FY1987 report showed that a full 60% of CSBG funds provide direct services which are not otherwise available.
- 20% of CSBG is used to meet the many emergencies faced by the poor, including energy needs. These monies pay for intervening in a crisis, providing donated goods or cash, and setting the family back on a normal course before long-term dependency or even family break-up sets in. Our state and local officials tell us it is becoming more and more difficult to intervene effectively to keep a family from becoming a major consumer of federal and state aid.
- 15% of the funds underwrite the raising and coordination of resources from states, local governments, businesses, and charities in low-income communities. CSBG-funded activities generate 1.3 times as much local and private funding for the poor as the CSBG dollars.
- Also from the FY1987 report, on average nationwide, one quarter of CSBG funds on a local level pay for comprehensive case management.
- Without CSBG, there would be no way in most counties to assess family needs in a comprehensive manner or to assemble a custom-made package to help families work their way out of poverty.

The role of CAA's is most commonly understood to be that of "program operator" for a variety of federal, state, and locally funded on-going social and economic development programs. Included in these are the programs traditionally associated with CAA's: Head Start, Weatherization, and LIHEAP. In some states, these services have been expanded to include commodity food distribution, elderly nutrition programs, and welfare reform programs.

However, the most important role CAA's play is that of the agent for social and economic development in their communities. CSBG is the catalyst to that process. The ongoing identification of unmet needs of low income households in local communities and facilitation of the planning, development, and implementation of strategies to meet those needs is a process which is dependent on the CSBG.

These activities are not only what the CAA's must do, but are what they do best and are what they were intended to do when the Economic Opportunity Act was signed into law in 1964. These strategies can include improving the coordination of existing programs, initiating new or expanded programs, or assisting other institutions in becoming more sensitive to the needs of their low income constituents so that they can modify or initiate programs to better meet those needs.

Now, if I may, Mr. Chairman, I want to discuss some examples of the effective use of CSBG funds by Community Action Agencies.

- **OREGON:**

As a result of drought conditions in 1988 and 1989, as many as 10,000 migrant and seasonal farmworkers were stranded in Oregon. These workers had come for the harvest, but the harsh weather conditions had resulted in poor crop yields. Consequently, there was not enough work for the thousands of migrant farmworkers who had come to the state.

The migrant workers were stranded with no money, no transportation, little or no food, and inadequate housing.

The Oregon CAA's were the leading agencies in resolving this crisis. They used CSBG dollars to provide emergency food, shelter, clothing, transportation, and other basic necessities.

Over 13,000 individuals needed and received assistance. The State of Oregon eventually appropriated $500,000 in emergency funds, which were funnelled through the CAA's. Because CAA's were already in place addressing the needs of the workers, the Agencies were able to effect a quick and efficient delivery of services for the State.

With the aid of CSBG funds and the flexibility those funds provide, Oregon Community Action Agencies operate a state-wide delivery system which enabled them to help solve this crisis involving a low-income population.

- **IOWA:**

Farmstead Foods, a Cedar Rapids meat packaging plant, closed its doors in early March. When the company folded, over 2,000 jobs were lost. Workers received less than two weeks notice of the plant closing.

Health insurance coverage was terminated, and the company did not have sufficient assets to meet its final payroll.

While the workers were still reeling from the sudden shock of losing their jobs, the local CAA stepped in. The CAA's provided weekly food boxes from its food reserve, arranged with the State of Iowa for a two-month extension in the LIHEAP intake period for those affected by the plant closing, and coordinated a community general assistance fund which now contains $20,000 in voluntary contributions. None of these services could have been provided without CSBG dollars.

The Hawkeye Area Community Action Program (the Cedar Rapids CAA) anticipates that the plant closing will increase demand for their Housing Counseling Services (which can arrange for deferment of mortgage payments and assist with rental payments).

The CAA was the first agency to provide assistance to these workers. While the State is still mobilizing its bureaucracy to provide job training and relocation assistance, CSBG funds gave the CAA the flexibility to step in immediately to help those in need.

- **NORTH DAKOTA:**

100% of North Dakota is served by seven CAA's. The current total amount of CSBG funds the state receives is approximately $834,000.

One project which involves all seven of the CAA's in the state is the Self Reliance Program. It is an innovative partnership which has at its goal enabling low income clients to become self-sufficient and less dependent on public assistance.

The Self Reliance Program began as a demonstration project two years ago under the CSBG-DPP program and is now administered with CSBG funds. The North Dakota Department of Human Services has also provided significant funding, the Bank of North Dakota has signed on with job training and job creation activities, and the Governor has allowed some JTPA funds to be earmarked for fifty Self Reliance participants.

Case workers or Self Reliance Coordinators across the state guide low-income clients through the maze of social services available. The process begins by focusing on an individual's or a family's immediate needs. Clients then continue the process by learning to assess their own needs and planning how to work their way off public assistance. The case management approach has had a significant and measurable impact in lowering the level of dependency of the Self Reliance participants. The Southeast North Dakota CAA reports that 25 of the 85 families served by their Agency are now self-sufficient.

The success of the Self Reliance Program can be attributed to the flexible nature of the demonstration program and the CSBG, as well as the general ability of CAA's to provide innovative new approaches to eradicating poverty.

Mr. Chairman, every year CSBG must undertake three significant battles in order for Community Action Agencies to survive.

First, because in eight of the last ten years the Reagan-Bush budgets have requested the termination of the Community Services Block Grant, we have to fight the perception that somehow the program is not working just because the OMB doesn't want to fund it.

Second, every year the Community Services Block Grant faces a difficult time in the Appropriations process. One leading member of this committee told me that he has never had to work harder for a $5 million increase in any program's funds.

Finally, HHS is always slow to release the funds, reluctant to provide the necessary data, and unwilling to include CSBG and Community Action Agencies in its agenda.

Mr. Chairman, the Community Services Block Grant is going to be overwhelmingly reauthorized this year on a bi-partisan basis. With the changes that we are making in the authorizing bill, I would expect HHS to be more helpful to the program in the future.

Mr. Chairman, I would hope that, given the demonstrated importance of CSBG and its nearly flat funding for ten, long years, the Subcommittee will look favorably at a funding level close to the authorized amount of $451 million for the entire program, including the discretionary programs.

I also continue to recommend full funding for the Demonstration Partnership Program ($10 million) and, very importantly, full funding for the community services portion of the McKinney Act.

Senator BURDICK. If the White House's recommendation is imple-
ented and carried out, how many community action programs or
encies go out of business?

Mr. BRADLEY. We have—I am not quite sure how many commu-
ty action agencies there are. HHS has not collected much data,
t we think that there is approximately 1,200, pulling down—
encies getting resources from the community services block
ant. Of that, the last serious evaluation of closure showed about
percent would close. Just about all of the community action
encies in the rural areas would close, and our assumption is, in
ur State, all seven would close.

Senator BURDICK. Thank you.

Mr. BRADLEY. Thank you.

ATEMENT OF C.A. "MACK" McKINNEY, LEGISLATIVE COUNSEL, NONCOMMISSIONED OFFICERS ASSOCIATION OF THE U.S.A.

Senator BURDICK. Mack McKinney, legislative counsel, Noncommissioned Officers Association of the U.S.A. Welcome.

Mr. MCKINNEY. Mr. Chairman, the National Military Families
ssociation, NMFA, joins me with my association, the Noncommis-
oned Officers Association, in urging the subcommittee to approve
ll funding for the Impact Aid Program at $835 million.

The administration's request for $660.9 million is 9.8 percent
low the fiscal year 1990 appropriated level. It again, recommends
e elimination of "b" children from the program. NCOA and
MFA oppose the elimination on the basis that adverse events
ve occurred over the past two decades, and will occur and are
curring in certain school districts that claim inadequate funding
r educating children of military personnel, and such occurrences
e mentioned in my prepared statement.

PREPARED STATEMENT

Mr. Chairman, NCOA and NMFA appreciate this opportunity to
pear, no matter how briefly, in behalf of the military parents of
ildren affected by reductions in impact aid funding. Again, the
vo organizations ask the subcommittee and Congress to be as gen-
ous as possible in order to furnish military children with the best
basic education programs.

Thank you, Mr. Chairman.

[The statement follows:]

STATEMENT OF C.A. "MACK" McKINNEY

Mr. Chairman. The original law governing federal support for impacted schools was enacted in 1951. It provided financial aid for the education of children of military personnel. In the ensuing year the law was amended to cover children of civil service employees (1953), Indian students (1958), and low-rent housing students (1976). According to the latest statistics available to the Association (NCOA) there are more than half a million military children eligible for impact aid, nearly 745,000 low-rent housing students, 647,000 children of federal civilian employees, and 103,500 Indian students.

Prior to 1969 impact aid funds were adequate to support entitlements. Thereafter, entitlements were prorated at 84.5 percent in 1970, 81.7 percent in 1976, 64.4 percent in 1985, and even less in the last five years. In fact, total appropriations have decreased during the FY 1980-FY 1989 time-frame by 11 percent. For FY 1991 the Administration is recommending $660.9 million with no provisions to fund payments for certain 3(d)(2)(B) or "b" children. These are children of military personnel and federal employees working but not living on federal installations.

The recommendation to again eliminate payments for certain "b" children is based on the Administration's premise that their presence "creates no major (significant) financial burden for local school districts." This is no more fact then to say payments are adequate to reimburse school districts for educating "a" children. Past experiences in withholding or reducing impact aid funds prove that school districts suffer both financially, and operationally. Beginning in 1970 with the Bellevue (NE) Public School District through 1987 when the Douglas (SD) School District was in danger, military impacted schools have faced tough decisions because appropriations were not sufficient to furnish students with the most basic of education programs. This has led to school closings, reductions in school programs or their termination, lawsuits, threats to charge tuitions or increase property taxes, bill the Department of Defense (DoD), and fire teachers. None of these actions has caused the need for impact aid funds to shrink nor has it solved any of the problems related to lower prorations.

In late 1989 and again this year NCOA has been approached with alarm by soldiers and airmen and their families concerning the possibility that schools may be closed on Fort Sam Houston and Lackland and Randolph Air Force Bases located in the San Antonio, Texas area. In correspondence with the affected schools, officials advise Association officers that reforms in the State of Texas reforms have forced school budgets to rise by 50 percent.

Since the schools are coterminous to the boundaries of the military installations, their students all live on-base. As such, these local independent school districts cannot raise taxes to obtain the additional funds required and, as NCOA understands the situation; the State of Texas has required schools to reduce the student-teacher ratio and undertake other costly measures without providing the necessary funds. Since the on-base school districts may not raise funds through taxes or bonds, the only reasonable answer is for the federal government to appropriate the necessary monies.

As with other military impacted schools, these schools pay teachers well, produce students who possess above average scholastic aptitude scores, have minuscule dropout rates and, most importantly "what good schools are supposed to do."

The very thought of these schools being in trouble because of a lack of impact aid funds appears to be contrary to the intent of Public Law 87-874. The law declares that the United States should provide "financial assistance for local education agencies upon which the United States has placed a financial burden." NCOA submits that the declaration was not to provide partial fundings but to reimburse schools in full for taxes not collected for educating Section 3 children.

It is indeed fortunate that Congress authorizes and appropriates greater fundings for impact aid, otherwise the Administration's request would be most inadequate. Nevertheless, the sum is insufficient to provide aid to the 1300 school districts serving military children.

There is nothing that can replace the need to educate the children of this nation. It is indeed worthy that the federal government provides funds to assist many less-fortunate children to achieve at least a 12th grade education. And it is commendable that the federal government authorizes and appropriates funds for school districts that are impacted with military and civilian personnel living and/or working on federal installations. However, as laudable as it may be, impact aid is taking a beating trying to compete with other Department of Education programs.

NCOA believes that the basic education of our country's youth, particularly those who desire to attain a competitive level of learning, is vital to the future well-being of the nation. One way to provide support of this goal is for Congress to finance that portion of impact aid to schools necessary for adequate public education of military and civilian children working on federal installations.

Thank you

Senator BURDICK. Thank you.

Will base closings that are being talked about affect impact aid's funding needs?

Mr. MCKINNEY. The bases may or may not be closed within the next year, and of course we are talking about the next fiscal year. Most of them will go for a 5-year period, and it is my humble opinion that most of the bases that are set for closure will probably hold out there as long as they possibly can, because you have got civilians in most of them, and they are going to have to be trained or transitioned in some way or another, and your military personnel are going to have to be transferred to other places, if not turned loose.

So, the effect of needing the impact aid continues to exist out there, Mr. Chairman.

Senator BURDICK. Thank you.

Mr. MCKINNEY. Thank you, sir.

STATEMENT OF CHARLES PATTERSON, SUPERINTENDENT, KILLEEN (TEXAS) INDEPENDENT SCHOOL DISTRICT

Senator BURDICK. Charles Patterson, superintendent of Killeen Independent School District. Welcome.

Mr. PATTERSON. Mr. Chairman, thank you, and I want to thank the preceding speaker who talked on a topic very near to my heart. I am Charles Patterson, superintendent of the Killeen Independent School District in Killeen, TX. Thank you for the opportunity to appear as a public witness for the Federal Impact Aid Program.

Our district—let me share three thoughts, a little about our district. We serve over 23,000 students, 13,000 of those students are military students; 6,000 of those students' parents live on base, for which we receive absolutely nothing, other than Federal impact aid, no local revenue. That is a little about our district.

Let me tell you about our children, your children. I think in all the numbers, impact aid gets very controversial, very diverse. They have numbers, they have formulas, they have waives, and what gets lost are the children.

Let me tell you about our children. When a military person makes a commitment to serve our country, they have some sacrifices they make, but they have some expectations, and one of those expectations is that they want their children to have a quality education, regardless of where they live, where they serve our country, either in the States or overseas. They have a right to that expectation.

These children are disrupted. They move every 2 years, 3 years. When they move, they often fall behind. They often miss 2 to 3 weeks of school as they make these moves. They fall behind, they miss school, they have different school years, different days of attendance. They also have other needs. Their parents often are assigned temporary duty, leaving that spouse with only one person to support them, and desperately needing our school help.

They have other needs. Our school district serves many language groups. We have primary languages of Korean, Japanese, Persian, German, and many other language groups. That takes extra resources to educate those youngsters.

These youngsters have many needs that need addressing, social, physical, emotional, and academic. They need counseling services as they adjust to a new curriculum, a new environment, new students, new friends, new teachers, and new policies. That is our children. What is our plot?

Last year, our district had massive budget cuts because of reduced funding. We cut over 170 personnel positions. We eliminated an elementary counseling program. We reduced remedial programs for our elementary students. We raised the size of our classes in our secondary schools.

Why? Because of reduced funding. We have over 1,500 military students, more than we had 3 years ago, and yet we have suffered reductions in military impact aid payments. That seems hardly fair for these youngsters, because of changed formulas or inadequate appropriations.

We have raised our tax rate over 51 percent in the last 2 years to accommodate this. Our district is property poor, we're 78 percent of the State average in our per pupil expenditures, raising only $8 per pupil for every penny on the tax rate, while the State of Texas averages $21.

PREPARED STATEMENT

We have reached a critical point for our children, for your children, for these people that have committed their lives in defense of our country. We would plead with you to appropriate the authorized amount of $835 million, and especially consider those category "a" students, where we so desperately are impacted by the military. We enjoy serving them, we appreciate their presence, but we need you support, Senator.

Thank you very much.

[The statement follows:]

STATEMENT OF CHARLES PATTERSON

MR. CHAIRMAN, MEMBERS OF THE COMMITTEE:

I AM CHARLES PATTERSON, SUPERINTENDENT OF THE KILLEEN INDEPENDENT SCHOOL DISTRICT IN KILLEEN, TEXAS. THANK YOU FOR ALLOWING ME THIS OPPORTUNITY TO APPEAR BEFORE YOU AS A PUBLIC WITNESS FOR THE FEDERAL IMPACT AID PROGRAM. I WOULD ALSO LIKE TO EXPRESS SPECIAL THANKS TO SENATORS PHIL GRAMM AND LLOYD BENTSEN OF TEXAS, FOR ASSISTING US WITH THIS PROGRAM AND TO ALL OF YOU WHO HAVE FOUGHT AND WORKED FOR IMPACT AID THROUGH THE YEARS. I AM HERE TODAY TO PLEAD FOR YOUR SUPPORT FOR INCREASED APPROPRIATIONS FOR THIS PROGRAM, ESPECIALLY FOR THE CATEGORY "A" STUDENTS.

AS YOU ARE AWARE, IMPACT AID PROVIDES FINANCIAL ASSISTANCE TO LOCAL SCHOOLS THAT HAVE BEEN IMPACTED BY FEDERAL ACTIVITY. IN THE KILLEEN SCHOOL DISTRICT, FOR EXAMPLE, THIS IMPACTION IS TWO-FOLD. ON THE ONE HAND, FORT HOOD OCCUPIES OVER 50% OF THE LAND WHICH IS THEREFORE UNTAXABLE. ON THE OTHER HAND, THOUSANDS OF STUDENTS BECOME STUDENTS IN OUR DISTRICT WHEN THEIR PARENTS ARE ASSIGNED TO AT FORT HOOD. THE RESULT OF THIS FEDERAL ACTIVITY IS THAT MORE CHILDREN ARE BROUGHT IN TO BE EDUCATED AND LESS MONEY IS ABLE TO BE RAISED LOCALLY TO PROVIDE FOR THESE CHILDREN'S EDUCATION.

THE SCHOOL DISTRICT IN WHICH I WORK SERVES ALMOST 23,000 CHILDREN. THIS YEAR, OVER 13,000 OF OUR STUDENTS ARE MILITARY DEPENDENTS AND REPRESENT ALMOST 58% OF OUR TOTAL ENROLLMENT. APPROXIMATELY 6,000 OF OUR MILITARY STUDENTS ARE CATEGORY "A" CHILDREN WHO LIVE ON THE BASE ITSELF. THEY PRODUCE NO LOCAL REVENUE FOR THE SCHOOL BECAUSE BOTH THEIR PLACE OF WORK AND THEIR RESIDENCE IS ON FEDERAL PROPERTY. IN ADDITION, OVER 760 OF OUR MILITARY CHILDREN ARE SPECIAL

EDUCATION STUDENTS. IT IS OBVIOUS THAT THE SCHOOL DISTRICT IN KILLEEN IS VERY HEAVILY IMPACTED BY FORT HOOD. WE DEPEND ON IMPACT AID TO PROVIDE THE FUNDS NECESSARY TO EDUCATE THESE CHILDREN. IMPACT AID IS A NECESSITY TO US, NOT A LUXURY.

IN RECENT YEARS OUR MILITARY ENROLLMENT HAS INCREASED, AND IN FACT, WE HAVE 1,500 MORE MILITARY CHILDREN NOW THAN WE DID THREE YEARS AGO. OUR IMPACT AID PAYMENTS, HOWEVER, HAVE ACTUALLY DECLINED BECAUSE OF CHANGES IN THE FORMULA AND INADEQUATE APPROPRIATIONS. THIS YEAR, OUR PER PUPIL PAYMENT FOR CATEGORY "A" CHILDREN IS LESS THAN IT WAS IN FY '87. FOR OUR CATEGORY "B" CHILDREN, WE RECEIVE NO ADDITIONAL FUNDS FOR THE NEW 1,100 "B" CHILDREN WE HAVE HAD SINCE FY '87. AS YOU CAN IMAGINE, THIS HAS CAUSED A BUDGET SHORTFALL. WE HAVE RAISED OUR LOCAL TAX RATE OVER 51% IN THE LAST TWO YEARS IN OUR ATTEMPTS TO OFFSET THIS SHORTFALL.

BECAUSE OVER HALF OF THE LAND IN OUR DISTRICT IS ON FEDERAL PROPERTY WE ARE A "PROPERTY-POOR" SCHOOL DISTRICT. IN OTHER WORDS, WE RAISE LESS THAN $8 PER PUPIL FOR EACH CENT ON THE TAX RATE. IN COMPARISON, THE AVERAGE SCHOOL IN TEXAS CAN RAISE OVER $21 PER PUPIL FOR EACH CENT ON THE TAX RATE. OUR PER PUPIL EXPENDITURE IN FY '89 WAS ONLY 78% OF THE STATE PER PUPIL EXPENDITURE. WE SPENT SLIGHTLY OVER $2900 PER PUPIL WHILE THE STATE AVERAGE WAS OVER $3700 PER PUPIL. WE ARE UNABLE TO RAISE ENOUGH LOCALLY TO OFFSET THE REDUCTIONS WE HAVE TAKEN IN IMPACT AID.

THE MECHANICS OF THE IMPACT AID PROGRAM ARE COMPLICATED AND DIFFICULT TO UNDERSTAND. THERE ARE VARIOUS FORMULAS AND NUMBERS FOR THE DIVERSE TYPES OF STUDENTS AND DISTRICTS. THE

IMPORTANCE OF THE PROGRAM, HOWEVER, IS NOT ABOUT THE NUMBERS, BUT IT IS ABOUT THE CHILDREN.

THE CHILDREN WE SERVE FOR THE MOST PART ARE THE SONS AND DAUGHTERS OF ENLISTED PERSONNEL. MANY OF THEM QUALIFY FOR FREE OR REDUCED LUNCH AND REMEDIATION SPECIAL PROGRAMS SUCH AS BASIC SKILLS AND CHAPTER I. THESE CHILDREN MOVE OFTEN, USUALLY EVERY TWO TO FOUR YEARS. WHEN THEIR PARENTS ARE TRANSFERRED FROM ONE POST TO ANOTHER THESE STUDENTS OFTEN MISS TWO TO THREE WEEKS OF SCHOOL. OFTEN THIS DISRUPTION IN ATTENDANCE RESULTS IN STUDENTS FALLING BEHIND IN THEIR SCHOOL WORK. IN MANY CASES, ONE OF THE CHILD'S PARENTS IS ASSIGNED TO TEMPORARY DUTY AWAY FROM HOME FOR UP TO SIX MONTHS AT A TIME, LEAVING THE CHILDREN WITH LESS SUPPORT AND SUPERVISION WHILE THE PARENT IS AWAY. OUR DISTRICT ALSO ENROLLS MANY CHILDREN WHO DO NOT SPEAK OR UNDERSTAND ENGLISH. IN THE KILLEEN SCHOOL DISTRICT, WE HAVE CHILDREN FROM MANY LANGUAGE GROUPS WHOSE PRIMARY LANGUAGE INCLUDES KOREAN, JAPANESE, GERMAN AND EVEN PERSIAN.

OUR STUDENTS HAVE SPECIAL NEEDS WHICH SHOULD BE ADDRESSED. MANY OF OUR STUDENTS ARE BEHIND ACADEMICALLY AND NEED SPECIAL REMEDIATION PROGRAMS IN ORDER TO CATCH UP. WE NEED THE RESOURCES TO ASSESS THE NEEDS OF THESE CHILDREN AS THEY ENTER OUR SCHOOLS SO THAT WE CAN DETERMINE THEIR ACADEMIC, SOCIAL, PHYSICAL AND EMOTIONAL NEEDS. THEN IT IS OUR OBLIGATION TO PROVIDE APPROPRIATE SERVICES TO THEM. THESE CHILDREN NEED COUNSELING SERVICES TO ASSIST THEM IN ADJUSTING TO A NEW ENVIRONMENT, A NEW CURRICULUM, NEW FRIENDS AND NEW POLICIES.

ALTHOUGH OUR CHILDREN HAVE THESE NEEDS, IT WAS NECESSARY FOR OUR DISTRICT TO INSTITUTE MASSIVE BUDGET CUTS FOR FY '90 SO

THAT WE COULD BALANCE THE BUDGET. THESE REDUCTIONS INCLUDED SUCH THINGS AS THE ELIMINATION OF OVER 170 PERSONNEL POSITIONS, OF WHICH OVER 100 WERE EITHER TEACHERS OR TEACHER AIDES. THESE REDUCTIONS ALSO INCLUDED THE ELIMINATION OF THE COUNSELING PROGRAM IN ELEMENTARY SCHOOL, ELIMINATING REMEDIAL PROGRAMS AT THE HIGH SCHOOL, INCREASING THE HIGH SCHOOL AND MIDDLE SCHOOL CLASS SIZES, REDUCING THE BASIC SKILLS REMEDIATION PROGRAMS AT THE ELEMENTARY SCHOOL AND REDUCING ELEMENTARY MUSIC AND PHYSICAL EDUCATION PROGRAMS . WE HAVE ALSO REDUCED ALLOCATIONS FOR INSTRUCTIONAL SUPPLIES, TRAVEL, MEDIA SERVICES, AND CO-CURRICULAR ACTIVITIES.

I BELIEVE WE HAVE REDUCED TO A CRITICAL POINT, AND THAT CHILDREN OF MILITARY PERSONNEL ARE BEING SHORT-CHANGED. FOR FY '91, BARRING UNFORESEEN ADDITIONAL FINANCIAL RESOURCES, WE WILL PROBABLY HAVE TO MAKE ADDITIONAL REDUCTIONS. THE END RESULT IS THAT OUR CHILDREN ARE NOT RECEIVING THE QUALITY OF EDUCATION THEY WOULD RECEIVE IN A NON-MILITARY IMPACTED SCHOOL DISTRICT.

MY PLEA TO YOU TODAY IS TO CONSIDER FUNDING IMPACT AID AT ITS FULLY AUTHORIZED AMOUNT OF $835 MILLION IN FY '91. I REALIZE THAT RESOURCES ARE LIMITED AND THAT YOU HAVE MANY DEMANDS UPON THOSE RESOURCES, BUT PLEASE CONSIDER THE CHILDREN. IF YOU ARE UNABLE TO FUND IMPACT AID AT $835 MILLION, I RESPECTFULLY ASK THAT YOU FUND CATEGORY "A" OF THE PROGRAM AT A MINIMUM OF $620 MILLLION, SO THAT WE WILL NOT HAVE TO IMPLEMENT FURTHER REDUCTIONS.

THANK YOU FOR YOUR TIME AND CONSIDERATION. I AM VERY GRATEFUL THAT YOU ALLOWED ME TO TESTIFY TODAY.

Senator BURDICK. Thank you. According to information I have from the committee, the impact aid for this coming year, fiscal year 1991 increased from $732 million to $835 million. That is over a $100 million increase.

Mr. PATTERSON. The $835 million is authorized, but what we are concerned about is the amount to be appropriated.

Senator BURDICK. You are right; it is the authorized level. But that is where we start, you know.

Mr. PATTERSON. The President's budget is very inadequate. We are losing yearly, and every year that we grow in military and lose funding, it gets more critical.

Senator BURDICK. Well, our recommendations coincide with yours. We will see what happens from now on.

Mr. PATTERSON. Thank you, sir. We appreciate your past support. Thank you.

STATEMENT OF ROBERTA HOUSMAN, VICE PRESIDENT, NATIONAL CENTER ON EMPLOYMENT AND DISABILITY ON BEHALF OF THE INTER-NATIONAL ASSOCIATION OF BUSINESS, INDUSTRY AND REHABILITATION

ACCOMPANIED BY CARL PULEO, PRESIDENT, INTER-NATIONAL ASSOCIATION OF BUSINESS, INDUSTRY AND REHABILITATION

Senator BURDICK. The next witness is Roberta Housman, vice president, the National Center on Employment and Disability, Albertson, NY.

You may proceed as you wish.

Ms. HOUSMAN. Thank you, Senator. Good morning, Senator. My name is Roberta Housman. I am the chairman of the Inter-National Association of Business, Industry and Rehabilitation, I-NABIR, which is the national association of projects with industry, PWI, programs. I am also the vice president of the Human Resources Center in Albertson, Long Island. With me is Carl Puleo, president of I-NABIR.

The President's fiscal 1991 budget called for level funding of $18.76 million for projects with industry. The program is authorized at $19.925 million. This request is $1.16 million below the amount authorized by the Rehabilitation Act.

We are disappointed and frustrated by the President's budget, because PWI is a successful and efficient means of placing persons with disabilities into competitive jobs. It has proven itself over the past 22 years, returning $3.42 for each Federal dollar spent on PWI in the first year alone. If there ever was a program that the Government should fund, it is one that pays back more than it costs.

PWI is a partnership between the business and labor and the rehabilitation communities, engaging the talent and leadership of private industry as partners in the rehabilitation process. This partnership will provide business and labor with the tools to implement the Americans With Disabilities Act.

In a nutshell, what makes this program different and effective is that it does not just rely on Government, but instead, business and labor play a real role. PWI is accountable. It has measurable objective criteria, against which the projects are measured. Standards require serving persons with severe disabilities and a high rate of placement at a minimum cost.

The year 1991 is a particularly important year for PWI. It is imperative that sufficient funds be available to continue funding all projects which meet or exceed compliance indicators, while also providing funds for new projects in some underserved areas.

If the additional $1.16 million is appropriated, almost 1,000 persons with disabilities will be trained and placed in competitive, labor market jobs. In addition, in just the first year of employment, $10.5 million will be earned by these PWI graduates; $2 million in FICA taxes will be paid. Over 100 SSI and SSDI recipients will be working. Over $1 million in SSI and SSDI payments will be saved, and an additional $879,000 in Federal income taxes will be paid. Please note that this is over $4 million in savings and payments for an additional $1.16 million in appropriations.

PREPARED STATEMENT

We appreciate the very strict budgetary limits faced by this subcommittee. However, we hope and trust that you will be able to fund PWI at its fully authorized level of $19.925 million, which will not only realize these savings, but most importantly, provide meaningful jobs and increased independence for more persons with disabilities.

I will be glad to answer any questions you may have. Thank you.

[The statement follows:]

STATEMENT OF ROBERTA HOUSMAN

Good morning Mr. Chairman. My name is Roberta Housman. I am the chairman of the Inter-National Association of Business, Industry and Rehabilitation (I-NABIR). I am also Vice President of the National Center on Employment and Disability, Human Resources Center in Albertson, Long Island. Accompanying me today is Carl Puleo, President of I-NABIR.

I-NABIR is the national association of Projects With Industry (PWI) programs. Our 97 members either have a PWI funded under the Rehabilitation Act of 1973 or have an interest in furthering the employment of persons with disabilities through cooperation between the business community, organized labor, trade associations and rehabilitation service providers.Projects With Industry has been part of the Rehabilitation Act since 1968 when the Department of Health, Education and Welfare was given authority to fund cooperative arrangements for rehabilitation organizations and private employers to develop job placement programs to provide competitive employment for persons with disabilities. Over the past 21 years PWI has funded many innovative projects which have included major corporations, unions, rehabilitation facilities, small businesses, advocacy organizations and national trade associations. PWI projects place thousands of persons with disabilities into jobs because rehabilitation and the private sector really work together.

The President's fiscal 1991 budget called for level funding of $18.76 million for Projects With Industry (Title VI, Part B of the Rehabilitation Act of 1973). The program is authorized at $19.925 million (Section 623). The President's request is $1.16 million below the amount authorized by the Rehabilitation Act, as amended.

PWI should be funded at its full authorized level of $19.925 for fiscal year 1991. We are disappointed and frustrated by the President's budget because this is a program that works, business supports, and is cost beneficial. PWI is a very successful and efficient means of placing persons with disabilities into competitive jobs in the community.

The 1986 Harris Poll indicates that two-thirds of working age people with disabilities are not in the work force although two-thirds of these people want to work. Eighty-two percent said that they would relinquish their government benefits in exchange for a full time job.

PWI returns $3.42 for each Federal dollar spent on PWI in the first year for persons with disabilities served. If there ever was a program that the government should fund it is one that pays back more than it costs.This is a compelling argument for increased funding.

PWI is a partnership between the business and labor communities and the rehabilitation community. The purpose of PWI is to, " promote opportunities for competitive employment of individuals with handicaps, to provide appropriate placement resources, ***to engage the talent and leadership of private industry as partners in the rehabilitation process***, to create practical settings for job readiness and training programs, and to secure the participation of private industry in identifying and providing job opportunities and the necessary skills and training to qualify people with handicaps for competitive jobs". (emphasis added) This relationship will be very important in implementing the Americans With Disabilities Act and in providing the business community with technical assistance. In a nutshell, what makes this program different and effective is that it doesn't just rely on government but instead, business and labor play a real role.

PWI is an accountable program. Standards for evaluation of all PWI projects were developed in 1985 and indicators of minimum compliance were established in 1988. PWI has measurable, objective criteria against which projects are evaluated. These standards include serving a certain percentage of persons with severe disabilities , a specific level of placement, and a minimum cost per placement.

1991 is a particularly important year for PWI. It is imperative that sufficient funds be available to continue funding all current projects which meet or exceed compliance indicators while also providing funds for new projects in underserved areas.

The accompanying fact sheet details what PWI can actually accomplish in one year based on information gathered by and provided by the Rehabilitation Services Administration.

What will result if the additional $1.16 million is appropriated?

- an additional 996 persons with disabilities will be trained and given jobs in the competitive labor market

- an additional $10,579,512 will be earned by these PWI graduates the first year

- an additional $2 million in FICA taxes will be paid the first year of employment

- an additional 109 SSI and SSDI recipients will be going to work

- an additional $1,151,385 in SSI and SSDI payments will be saved during the first year of employment

- an additional $879,468 in Federal income tax will be paid in the first year of employment

This is over $4 million in savings and payments for the additional $1.16 million in appropriations.

We appreciate the very strict budgetary limits faced by this subcommittee, however, we hope and trust that you will be able to fund PWI at its fully authorized level which will not only realize these savings but most importantly provide meaningful jobs and increased independence for more persons with disabilities.

Fact Sheet
Projects With Industry

Projects With Industry has been part of the Rehabilitation Act since 1968 when the Department of Health, Education and Welfare was given authority to fund cooperative arrangements for rehabilitation organizations and private employers to develop job placement programs to provide competitive employment for persons with disabilities. Over the past 22 years PWI has funded many innovative projects which have included major corporations, unions, rehabilitation facilities, small businesses, advocacy organizations and national trade associations.

The purpose of PWI is to, " promote opportunities for competitive employment of individuals with handicaps, to provide appropriate placement resources, to engage the talent and leadership of private industry as partners in the rehabilitation process, to create practical settings for job readiness and training programs, and to secure the participation of private industry in identifying and providing job opportunities and the necessary skills and training to qualify people with handicaps for competitive jobs". (Section 621(a)(1) of the Rehabilitation Act of 1973, as amended.)

In 1988 the Rehabilitation Services Administration collected the first comprehensive data from all of the current PWIs. This data, collected in August 1988 covered the period from October 1, 1986 to September 30, 1987. The total amount of Federal PWI funds reported was $15.75 million. Over 13,500 persons with disabilities were placed into competitive employment. More than 60% of these persons were severely disabled. Over 3000 were on Supplemental Security Income (SSI) or Social Security Disability Insurance prior to being placed into a job through PWI. The average cost per placement (Federal dollars) was $1164. The average person placed improved their income by $8260 a year. Their average earnings per year was $10,622.

Just as impressive, if not more so, is what these PWI graduates give back to their communities and to the Federal government when they get a job. Based on the above figures the PWI graduates for that one year will earn more than $143 million a year. This is money that will go back into our economy. The Social Security withholding tax (FICA) from the individuals and their new employers will total more than $27 million. For the 3000 former SSI and SSDI recipients the Federal government will save over $16 million a year. Assuming that the average PWI graduate is a single taxpayer with no dependents, the graduates from that one year will pay over $11.5 million in income taxes. For a Federal expenditure of $15.75 The Federal government will get back or save over $54 million in one year. This is $3.42 for each Federal dollar spent on PWI in one year. PWI graduates will continue working for many years and these savings will multiply.

Several major studies have shown that PWI has been successful in attaining its goals of placing disabled persons into competitive jobs. A 1983 study found that through its private sector linkages PWI was successful and that the diversity of organizations operating PWI's and the flexibility of the projects were important factors in its overall effectiveness. A 1982 study concluded "there is no doubt that a secure linkage between rehabilitation organizations and employers is the optimal avenue for disabled persons back into the economic mainstream."A 1986 study, mandated by the Rehabilitation Act amendments of 1984, concluded that, "In general, PWI projects are experiencing success in their efforts to assist persons with disabilities in obtaining competitive jobs. The relatively low cost per placement, especially for older projects, suggests that PWI projects are accomplishing their goals in an efficient manner."

For fiscal 1991 the President's budget called for level funding of $18.76 million. The program is authorized at $19.925 million.

PWI is part of the Rehabilitation Act of 1973 which is up for reauthorization in 1991.

Senator BURDICK. Do you think the authorized level is enough to meet the need?

Ms. HOUSMAN. Well, sir, it is what we have to work with, but we would like to see it at the authorized level. We feel that there is so much that can be done. Rehabilitation, the bottom line, is the person getting a job, and that is what PWI is here to do.

Senator BURDICK. We are recommending, as you know, $19.93 million.

Ms. HOUSMAN. We would appreciate that.

Senator BURDICK. More than the fiscal 1990 figure.

Ms. HOUSMAN. Thank you, sir.

STATEMENT OF DANIEL PERRY, EXECUTIVE DIRECTOR, ALLIANCE FOR AGING RESEARCH

Senator BURDICK. Our next witness is Daniel Perry, executive director, Alliance for Aging Research. Welcome to the committee.

Mr. PERRY. Good morning, Mr. Chairman. I am Daniel Perry. I am executive director of the Alliance for Aging Research. This is an organization which includes some of the Nation's leading scientists and medical researchers, also leaders from corporate America and major nonprofit foundations, and a bipartisan advisory council of some of your colleagues, Mr. Chairman, in the Senate and in the House. The Alliance for Aging Research supports important discovery research by the National Institute on Aging.

In the moments allotted to oral testimony, I would like to draw your attention to the aging of the American population, the high and growing incidence of chronic diseases and disabilities and the cost to older Americans. Call it the grain of America or the senior boom, or by any other title, the great demographic surge in numbers among the old and the very old will likely pose the greatest imaginable challenge for the next century, both to our Nation's health care system and to our financial resources.

Every day, more than 6,000 additional Americans turn 65. Just a few decades into the 21st century and nearly one-quarter of the U.S. population will be old enough to qualify for Medicare.

Of particular concern is the exponential rise of the over 85 population. At age 65, a person's risk is still mercifully low of being chronically disabled due to memory loss or because of failing vision or hearing or from extreme frailty or from a hip fracture. But at age 85, the odds of losing our independence due to such conditions is no better than one in three.

Because of earlier successes in this century in public health and medical research we have achieved the possibility of long life for nearly every American. Now we have a responsibility to ourselves, to older Americans and to the Federal Treasury to make it a priority to find the most effective ways to cure, prevent, or postpone the chronic diseases and disabling conditions that rob personal independence and financial security from so many older Americans.

Despite the leadership of this committee and its chairman in the past, aging research remains one of the lowest priorities in terms of the budget for health research. The President's budget request for fiscal year 1991 perpetuates the sorry state of affairs in which the National Institute on Aging, for one example, is able to fund fewer than one in five of the high priority research projects that come out of peer review.

A few weeks ago, the Pepper Commission unveiled its recommendations for long-term care, and one extremely important part of their report was a call for a research agenda to reduce the need for long-term care. The commissioners, both Republicans and Democrats alike, said the Federal Government should move toward a funding level of $1 billion a year to prevent and postpone the chronic diseases of aging.

PREPARED STATEMENT

Given the tight budget times, Mr. Chairman, nevertheless, I urge you to look at the Pepper Commission and their bipartisan report, and try to work toward that level of $1 billion a year for these conditions.

I appreciate the chance to testify before you this morning.

[The statement follows:]

STATEMENT OF DANIEL PERRY

Mr. Chairman and distinguished members of this Subcommittee, it is my pleasure to be able to outline for you the concerns of the Alliance for Aging Research regarding the President's proposed fiscal year 1991 budget.

The United States is at the beginning of a demographic revolution. Each day over 6,000 Americans celebrate their 65th birthday. Currently, Americans over age 65 represent over 12 percent of the population. The oldest old, Americans age 85 and older, represent the fastest growing segment of the population. It is estimated that the 1990 Census will count a record number of 57,000 Americans age 100 and over.

This year, care for older Americans will represent about one-third of the nation's total health care bill -- a sum of more than $215 billion this year alone. By the year 2010, present trends suggest that older Americans will require about one-half of an estimated national health care bill of over $1.5 trillion -- three times the cost of health care today.

The growing cost of chronic long-term care is already putting tremendous strains on our health care system. Fortunately, through research in human aging, there are some important steps this Subcommittee can take to help reduce the cost of treating chronic, long-term illnesses and conditions.

Last year, the Alliance for Aging Research, together with a coalition of 20 of the nation's most prominent health care organizations led by former, Health, Education and Welfare Secretary Joseph A. Califano, Jr., announced Project Independence for Older Americans. A cornerstone of this effort is to focus research attention and resources to attack real problems of aging -- problems like physical frailty, memory loss, incontinence and hearing loss -- that too often rob older people of their personal independence.

This effort has received bipartisan support. President Bush has noted, "We should try to reduce the need for care by devoting significant research attention to the prevention and cure of debilitating illnesses - illnesses like Alzheimer's, arthritis, and osteoporosis -- that can keep us from caring for ourselves."

Recently, the Pepper Commission was even more specific as to the scope and size of such a research effort designed to reduce dependency. The Commission, in its final report recommended, "The federal government should move aggressively to contain costs and mitigate human suffering by funding a research and development program aimed at preventing, delaying and dealing with long-term illnesses and disabilities. This effort should include research on outcome measures and national practice guidelines in long-term care. That effort should move toward a funding level of $1 billion annually."

Mr. Chairman, this nation is unfortunately a long way off from meeting the $1 billion target the Pepper Commission and others have said is necessary if we are to make headway in providing independence for older Americans. Budget constraints at the National Institute on Aging have led to a decrease in the number of new and competing awards from 192 in FY 1989 to 156 in FY 1990. Under the President's proposed budget for fiscal year 1991, real spending at the NIA will decrease by over $5 million, reduced from $239.5 million in fiscal year 1990 to $234.4 million in fiscal year 1991 after adjusted for inflation.

It is time to make a real commitment that will move us toward $1 billion to keep older Americans independent.

National Institute on Aging Recommendations

The National Institute on Aging is the demonstrated leader in research efforts to provide independence for older Americans. As the lead agency in such an effort, the NIA budget should be increased to $600 million. Mr. Chairman, I fully understand the financial limits of the budget you have to work with. We must also make a prudent investment in improving the health and independence of our growing population of older Americans. Boosting the NIA's budget to $400 million in FY 1991 would be a good start.

Some important steps in that direction should include:

-- Moving closer to the Congressional Advisory Panel on Alzheimer's Disease recommendation by raising NIA efforts in Alzheimer's research to $169 million.

-- Stepping up efforts, as noted in last year's report language by this Subcommittee, in the area of cellular and molecular processes of aging and cancer. Included in this effort, at a recommended funding level of $30 million, should be a new research and prevention initiative aimed at reducing breast cancer.

-- Programs that would reduce frailty, falls and fractures due to bone-thinning osteoporosis need to be increased to $25 million at the NIA.

-- Rehabilitation from chronic conditions like stroke needs to be a greater focus of biomedical, social and behavioral research. This effort should receive $17 million.

-- More research in productivity, work and retirement could help our nation confront a growing worker shortage. Efforts such as the new national longitudinal survey on health and retirement would require approximately $4 million.

-- To help meet the shortfall of trained clinicians in geriatric medicine, full funding, $10.5 million, for the Claude D. Pepper Geriatric Research and Training Center Awards is recommended.

-- Minorities differ substantially from the overall population in many respects, including health and longevity. We need to step up our efforts to study the effects of specific conditions and disease processes on minority populations. An increase of funding to $8 million in this area is recommended.

-- Sensory, cognitive and motor impairments frequently limit the independence of older Americans, yet current assessment methods often fail to detect the cause and nature of such disorders in older people. To better improve detection of these impairments and other related research, $15 million is recommended.

-- With growing evidence linking life style to achieving successful aging, more research in areas such a injury prevention, smoking cessation and self-care are needed. A funding level of $60 million is recommended for this area.

-- Older rural residents face some unique problems in being served by health care. A funding level of $7 million for Exploratory Centers to study the physical, social, cultural and economic factors affecting the health and well-being of older rural residents is recommended.

-- Chronic sleep disorders afflict over half of all Americans over age 65 and about two-thirds of those who live in long-term care facilities. Increasing research on sleep disorders to $7.5 billion is recommended.

– More basic and clinical research is needed to improve the use of medications by older people. Side affects from improper use or prescription of medications can result in problems such as dizziness and falls, incontinence and confusion in older people. To help improve the use of medications, the Geriatric Pharmacology program should be increased to $15 million.

Human Genome Project

One of the greatest scientific opportunities since the invention of the microscope is the current effort to map and sequence the full range of DNA know as the Human Genome Project. This effort has the potential to unlock the secrets to over 3,000 genetic diseases like Alzheimer's disease, cancer and cardiovascular diseases.

Recently, Dr. James Watson, Director of the National Center for Human Genome Research, spoke to a meeting of our organization. Dr. Watson predicted that a breakthrough in the genetic basis of Alzheimer's Disease could be as close as five years away as a result of the Genome Project.

I am pleased to report that most of the planning for this major undertaking has been completed and our scientists are beginning their important work. We must provide them the tools they need to complete this project which is so critical to the health of millions. The National Center for Human Genome Research should receive its full request of $109 million.

STATEMENT OF STEPHEN P. STRICKLAND, PRESIDENT, NATIONAL PEACE INSTITUTE FOUNDATION

ACCOMPANIED BY FRANCES HUMPHREY HOWARD

Senator **BURDICK**. Frances Humphrey Howard and Dr. Stephen Strickland, president, the National Peace Institute Foundation. I am pleased to see Frances Howard here today. I recall a lot of good memories with her departed, political brother.

Mrs. **HOWARD**. Good morning, Senator.

Senator **BURDICK**. Good to see you.

Mrs. **HOWARD**. Thank you. Stephen Strickland, the president of the National Peace Institute Foundation, will make the major presentation on behalf of this very important organization, the National Peace Institute, which the Congress created 6 years ago.

Dr. **STRICKLAND**. Mr. Chairman, it is a great pleasure to be here, sir. I am an admirer of yours and of your father before you.

I have been here 30 years in this city, and in that period of time, I have done things that make me want to say a word of support for some of the previous witnesses. I ran the National Advisory Council on the Education of Disadvantaged Children, and I know that Head Start is one of the great programs created by Congress and President Johnson.

I am an historian and analyst of the National Institutes of Health, and I know that the request for increased support for the Institute of Aging is enormously valid. And Frances and I were just saying we wished we could say a word of support for every one of the witnesses who have preceded us.

You have, in this appropriations process, really, a magnificent opportunity, Senator Burdick, to help your colleagues and the Congress as a whole and the country as a whole move from a defense-based economy to a peace-based economy, and to taking care of human needs and to taking care of the future of the peace process.

Congress, in its wisdom 6 years ago, responding to really a national demand, 50,000 people and the National Peace Academy Campaign requested it, and Congress responded by creating one Government agency devoted to peace through education, research, and service. That is the U.S. Institute of Peace.

Six years since its inception, it is still a very small agency, and yet it does critically important work. It supports scholars and analysts and diplomats and practitioners of conflict resolution across our country. You know, sir, that the University of North Dakota has a fine peace study center at the campus at Grand Forks.

And what I wanted to say this morning in supplement to our written testimony is simply that this small creature of Congress deserves the maximum that Congress has said it can have as an appropriation, and that is, the very small amount of $10 million. The request of the Institute is only for $9.2 million.

Scholars are waiting to be trained, practitioners are waiting to do more to help with the transition to peace and democracy in Eastern Europe, and by the way, the Peace Institute, under Ambassador Lewis, has organized such a study group that is going to be enormously helpful to you and to the administration. He should have the resources to do that for every major trouble spot in the world, but he does not.

The demand is great, the need is great, the time is right. Basically, sir, this is an agency, although placed in the executive branch of Government, that really is the child of Congress. Congress insisted upon it, Congress has nurtured it, this committee has nurtured it through appropriations. Now is the time to give it the boost that it needs. Now is the time to take advantage of what has gone on in the last 6 years and to position it even more strongly to serve us all in the future.

PREPARED STATEMENT

Our request, endorsed by our board, by our board of advisors, Mrs. Howard, is for an appropriation of $10 million, and if there is any doubt as to whether the Institute can use it and precisely how, I would suggest, Mr. Chairman, that the committee ask the president of the U.S. Institute of Peace how he might use that small, additional amount that we are recommending, $800,000, for 1990. I can assure you that it will be well used, that all of us will benefit and that the world will as well. Thank you, sir.

[The statement follows:]

STATEMENT OF STEPHEN P. STRICKLAND

Mr. Chairman, and members of the Committee, my name is Stephen P. Strickland, and I am President of the National Peace Institute Foundation. As members of this Committee know, the Foundation grew out of the National Peace Academy Campaign, which was instrumental in the creation by Congress of the United States Institute of Peace, six years ago this year.

Our Foundation is not officially affiliated with the United States Institute of Peace. Instead, we are an independent organization with approximately 14,000 members from every state in the union who financially support our activities. We also remain in touch with most of those 50,000 Americans who, beginning in the 1970's, worked along with Congress to create a Peace Institute. Some of our Board members served on the Study Commission created by Congress and worked alongside members of both houses of Congress who were on that Commission. Our Foundation members felt a deep sense of gratification when Congress created the U.S. Institute of Peace and we retain the keenest possible interest in the Institute.

Our purpose here today is a simple one. It is to urge this Committee -- which has been so supportive of the U.S. Institute of Peace in the past -- to continue and indeed to increase that support. Mr. Chairman, I hope that you and your colleagues on this Committee and in the Senate as a whole, feel a sense of satisfaction that the idea you adopted and the instrument you created for the expansion of our government's and our nation's peacemaking capacity in 1984 has now come of age; that with respect to policymaking and to public education in the cause of peacebuilding, the U.S. Institute of Peace is moving into a centrally important position.

My reading of the history of the Institute's establishment is that one powerful motive for Congressional action was a deep sense of dismay over the dreadful consequences of having approached every international trouble spot in the 1960's and the

1970's in a belligerent mode. So Congress created the Institute to help the government and the nation develop new knowledge about the bases of violent conflicts, and about how to avoid or resolve them in the future. Mr. Chairman, the future has arrived.

No one foresaw the possibility that 1989 would bring much of the world closer to peace and democracy in the dramatic ways that have occurred. No one can predict precisely how this movement will unfold, or, indeed, whether it is certain and inexorable, or reversible. But every thinking person knows that the future, even though filled with promise, may well to be more complicated than the recent past. Peace has broken out in Eastern Europe, but so have latent ethnic hostilities. Democracy has returned to some of our neighbor nations to the South, but acute economic and political problems remain with such intensity that new conflicts are entirely possible, even likely.

Now is the time when peacebuilders and international conflict resolvers are needed in greater numbers and with the requisite knowledge and skills. Now is the moment when we must resolve to stay ahead of events -- in our study and thinking, planning and training -- lest once again we be overtaken by them.

Fortunately, in the United States Institute of Peace, under the leadership of its President, Ambassador Samuel Lewis, we have an agency which, for five years, has been preparing for the new era now dawning and which is now ready to assume a larger role on behalf of us all.

A few weeks ago, Ambassador Lewis reported to this Committee how the U.S. Institute many months ago convened a study group of scholars and diplomats to examine potential conflicts that could arise in Eastern Europe over the next five years even if Soviet control continues to recede, and how violent outbreaks might be forestalled. Encouraged by the State Department, this effort is going to prove enormously valuable to our policymakers, including the Congress of the United States. We at the National Peace Institute Foundation applaud this effort. We believe strongly that similar efforts are needed with respect to Latin America, Southern Africa, Northeastern Africa, Southeastern Asia, and the Middle East. But the Institute cannot undertake such additional, critically important efforts with the small budget it currently has.

Ambassador Lewis also reported to this Committee on a number of grants to educational institutions in several parts of the country, having to do with peace and conflict resolution curriculum development and teacher training. But the fact is that there are scores of additional institutions which want and have the intellectual and broad institutional capacity to undertake such programs -- to help train more peacemakers for the future -- but which have no chance of receiving even token support from the U.S. Institute because of the Institute's limited funds. Now is the time to expand the base of young Americans who wish to become skilled peacebuilders and conflict resolvers. There is a simple way to do so -- by increasing the Institute's budget.

From official testimony presented to you by Ambassador Lewis of the U.S. Institute, you also learned of a plan to expand the Institute's library capacity to make more easily available -- to journalists, students, scholarly researchers, independent analysts, educators and librarians throughout the country -- the best and most current peace-related research. That effort is altogether laudatory and important, but truly ought to be expanded and extended, and rapidly. The Institute's peace research library could in fact become a comprehensive national system, broadly accessible and very "user friendly", if the Institute had more resources to put into it.

Indeed, Mr. Chairman, almost every existing program of the U.S. Institute of Peace, including that devoted to public education, ought to be expanded. New opportunities for helping the transition to peacetime are being presented to the Institute every week. The Institute's current budget blocks both possibilities.

The U.S. Institute of Peace has requested $9.2 million for fiscal year 1991. This would be a 17% increase for the Institute over the amount appropriated last year. However, in dollar terms, Mr. Chairman, you and your colleagues can recognize instantly that the amount being requested, regardless of the percentage increase, is a minuscule item in the federal budget. It is an exceedingly small sum compared to the importance of the challenge and the relevance of the Institute's work. Congress in its wisdom actually authorized a ceiling of $10 million for the Institute for fiscal year 1991. Our Foundation's Board of Directors, and our members, strongly urge that this Committee appropriate the full authorized amount for next year.

The world is at a crossroads. So is our government and so, hence, is this Committee. The superpowers have backed away from war. More than ever before, we in the United States need all the intellectual resources we can develop and marshal, to safeguard and expand peace and to avoid new kinds of violent conflicts. Fortunately, we have in the U.S. Institute of Peace an institution prepared to help take on the new challenge. We have an agency which, under the mandate given it by Congress in 1984 and under the annual appropriations you have provided, has gradually developed capacities of leadership and service, now ready to be put to use.

All of us are keenly mindful of fiscal stringencies and of other urgent needs. But surely, Mr. Chairman, an appropriation of $10 million for the one U.S. Government entity devoted exclusively to peacemaking is a minimum we as a nation ought to provide. As the world moves hesitantly into a new, hopeful, but also hazardous era, we urge you and your colleagues to continue your pioneering, to give a strong boost to the agency you so wisely created six years ago so that, in turn, the U.S. Institute of Peace can more strongly boost the world's chances for lasting peace.

STEPHEN P. STRICKLAND, PRESIDENT/EXECUTIVE DIRECTOR

Dr. Stephen P Strickland is the President and Executive Director of the National Peace Institute Foundation and is responsible for day-to-day operation and long-range planning. From 1985 to 1988 Dr. Strickland was Senior Associate at the Kettering Foundation. At Kettering he was advisor for development of international programs and public outreach and coordinator of the foundation's program on supplemental diplomacy in the Western Hemisphere.

Prior to his position at Kettering, he served for eight years as vice president of the Aspen Institute for Humanistic Studies. Among his responsibilities at the Aspen Institute were oversight of the development of the center at Wye Plantation and coordination of Latin American programs, including the project on International Governance in the Western Hemisphere. He was founder and interim director of the Aspen Institute Italy in 1984. In prior years, Stephen Strickland directed the President's Commission on White House Fellows and was a senior Congressional staff member.

Mission

All people share a vision of a peaceful, just and secure world. The National Peace Institute Foundation links this vision with the growing knowledge and practice of the peaceful resolution of conflict.

We take pride in the fact that our National Peace Academy Campaign mobilized 45,000 citizens to secure the establishment of the United States Institute of Peace. The Campaign affirmed our belief in the power of concerned citizens working together to make a difference. We have a special commitment to the further growth of the Institute.

The Foundation's wider purpose is to promote peacebuilding and peacemaking throughout our own country and in the world. We seek to empower citizens and governments with the perspectives and skills required to avoid violent conflict and to convert potentially destructive tensions into positive energies for progress. Our objective is to integrate conflict resolution into the mainstream of national and international life.

Program

Through the network of our Regional Councils, we work cooperatively with local groups to promote the United States Institute of Peace and to sponsor events on peacemaking and conflict resolution. Our newsletter, the Peace Institute Reporter, serves as a national forum for peace educators and institutions. As a non-governmental member of the United Nations and in other ways, we participate in a global community of peacemakers.

Membership

An active, involved membership is key to the Foundation's past and future achievements. We welcome as members both individuals and institutions who share this vision for our common future.

Mrs. **Howard**. Senator, I want to add that I am so happy to be here this morning, not only for the testimony that was given on all of these programs, such as Head Start, community block grants and so forth, but happy to be here because my brother, Senator Humphrey, would have revelled in the fact that there is in existence, a national peace institute.

And he believed that peace was a living process, which the Peace Institute carries out. He believed that peace is something that is not static. And I was looking this morning, at about 8 o'clock, through a book called "The Wit and Wisdom of Hubert Humphrey," and I found these passages about peace. Hubert was always making speeches, as you know, Senator, and one of the speeches was in 1967, at which he said, "The building of peace is like the creation of a great cathedral. It doesn't come by a magic stroke or even in a decade. It requires generations in the hands of the master architect and in the work of many."

He also added that, "Peace is not passive; it's active. Peace is not appeasement; it's strength. Peace does not just happen, it requires work." And that is why the greatness of a nation is not determined by its ultimate accomplishments, but more importantly, by its significant beginnings, and the National Peace Institute has made a very significant beginning that will develop and mature into a great army of people who understand peace, conflict resolution.

Thank you for having us here, sir.

Senator **Burdick**. If I might add a little bit to what you have already said, I have heard those speeches myself, and I can verify everything you have said this morning. Hubert was just great, particularly on this issue.

Mrs. **Howard**. Thank you.

Mr. **Strickland**. Thank you, sir.

STATEMENT OF EMILY DeROCCO, EXECUTIVE VICE PRESIDENT, INTERSTATE CONFERENCE OF EMPLOYMENT SECURITY AGENCIES, INC.

Senator **Burdick**. Our next witness will be Emily DeRocco, Interstate Conference of Employment Security Agencies.

Welcome to the committee.

Ms. **DeRocco**. Thank you, Senator Burdick. I am pleased to be here representing ICESA's current president, Mike Deisz, who is, as you know, executive director of the job service of North Dakota as well.

While the primary focus of our testimony is on the fiscal year 1991 funding levels for employment security, it is essential that I take a moment to update you on the current, funding crisis in the Unemployment Insurance Program. Simply stated, claims for unemployment benefits are substantially higher than was anticipated in the 1990 budget, resulting in a $100 million shortfall. The Department of Labor responded to this situation by reducing the allocation for all our State agencies by 6.7 percent. Many States have already closed offices and have been forced to lay off personnel. As a result, service to unemployed workers in America has been severely impacted. We are seeing long lines at many State offices where claims are filed and reduced staffs in many States are having difficulty making benefit payments to unemployed individuals in a timely way. Unless a supplemental appropriation of $100 million is forthcoming, more drastic actions will occur across a larger network of States.

Adequate revenues do exist, as you know, in the "Employment Security Administration" account, and we are not asking that general revenues be appropriated. Rather we are asking that those dedicated taxes established to administer the UI system properly, be spent for that purpose. We respectfully request your assistance in this regard.

For fiscal year 1991, the administration's proposal to fund State employment service operations at $722 million represents a reduction of $57 million from the 1990 level. The $722 million would be the lowest dollar amount allocated for operation of the employment service since the early 1980's.

As the dollars available to us have been reduced, we have seen major increases in the cost of operations and experienced dramatic increases in the size of the work force we are supposed to serve. The proposed reduction to $722 million would be devastating for our system. We are asking you to consider a minimum of $850 million for fiscal year 1991, just to continue our basic operations.

Last year, this subcommittee was instrumental in providing for the first time moneys for employment service automation. The States are a long way from a productive level of automation, and we would appreciate your consideration of continuing this investment strategy and consideration of $25 million for fiscal year 1991 for ES automation.

PREPARED STATEMENT

The President's request for unemployment insurance for 1991 is based on assumptions that unemployment will be higher than was originally forecasted for 1990, but lower than the current estimates for the 1990 fiscal year. If their projections are accurate, resources for UI will be at about the same level, and this level provides fewer permanent staff than is reasonable to serve the unemployed workers of America. We urge you to provide a higher base staff level in fiscal year 1991 to lessen the impact of unanticipated increases in unemployment as we have experienced this year.

I thank you for the opportunity to testify and would be pleased to answer any questions you might have.

[The statement follows:]

STATEMENT OF THE INTERSTATE CONFERENCE OF EMPLOYMENT SECURITY AGENCIES, INC.

Mr. Chairman, members of the Subcommittee, my name is Mike Deisz. I am President of the Interstate Conference of Employment Security Agencies, Inc. (ICESA), and Executive Director of Job Service North Dakota. I am pleased to present our views on the funding needs of Employment Security programs.

CURRENT CRISIS IN UI FUNDING

While the primary focus of our statement concerns FY 1991 Employment Security funding levels, it is essential that we update you on the current funding crisis affecting the Unemployment Insurance Program. Simply stated, claims for unemployment benefits are substantially higher than was anticipated in the FY 1990 budget, resulting in an approximate $100 million shortfall. The Department of Labor has responded to this shortfall by reducing the base allocation for State Employment Security Agencies by 6.7 percent. Many states have already been forced to lay off personnel, close offices and institute other cost saving measures. As a result, service to unemployed workers has been severely impacted. We are seeing long lines at many offices where claims are filed, and reduced staffs in many states are having difficulty making prompt payments to unemployed individuals. Unless a supplemental appropriation of $100 million is forthcoming, more drastic actions are likely to occur over a larger network of states.

Secretary of Labor Elizabeth Dole has indicated that the Administration will not seek a supplemental in response to this most serious issue. We strongly encourage you and the members of this Subcommittee to find an expeditious solution to this urgent problem.

Adequate revenues, collected from employers under the Federal Unemployment Tax Act (FUTA), sit idle in the Employment Security Administration Account (ESAA), while this crisis lives on. Instead of being appropriated for their intended purpose, these revenues continue to be used to mask the deficit. We are not, therefore, requesting that general revenues be appropriated; rather, we are asking that the dedicated taxes established to administer properly the Unemployment Insurance System be spent for this purpose. We again respectfully request your assistance to help us serve those who are legally entitled to unemployment benefits.

FY 1991 FUNDING FOR EMPLOYMENT SECURITY PROGRAMS

Employment Service

Mr. Chairman, the Administration's proposal to fund State Employment Service operations at $722 million in FY 1991 represents a reduction of $57 million from the FY 1990 appropriated level. The $722 million figure would be the lowest dollar amount allocated for the operation of the public Employment Service since the early 1980s. We are including an attachment to our written testimony which shows the funding levels for the Employment Service since 1983, and the erosion to the Employment Service allocations which has resulted from inflation during that period of time.

As the buying power of the dollars available to the Employment Service has diminished, we have seen major increases in the cost of operations as average salary levels and other costs have grown. Additionally, we have experienced dramatic increases in the size of the work force which the system is designed to serve. Changing technology and the reality of global competition have resulted in dislocations in the work force. What this means is that more workers are being dislocated permanently from their former employment, and new jobs are being created which require different skills and different opportunities for access. The need for services provided by the public Employment Service has increased tremendously; yet the resources to address those needs continue to erode.

The public Employment Service has a long history of responding to the changing needs of the job market and the employers and workers who are affected by those changes. We are submitting for the record a copy of a recent publication entitled "The Employment Service Information Exchange Forums" which attests to the flexibility and responsiveness of our system.

The funding request for FY 1991 is a continuation of a long-term trend where the Administration has proposed reduced funding levels for the Employment Service. With your support as well as that of Mr. Byrd and others, we have managed to avoid these drastic cuts.

The proposed reduction to $722 million for FY 1991 would be devastating for a system that has already been stretched beyond the maximum and a system that is, on a day-to-day basis, having to cut back on the quality and level of service so much needed by our workers and employers.

For FY 1991, we are requesting that a minimum of $850 million be appropriated for the Employment Service. This level will allow the system to continue basic operations while our organization completes an analysis of future funding needs, to meet the growing demand for services.

Last year, Mr. Chairman, you were instrumental in securing for the first time, separately identified ES automation funds. The $12.5 million appropriated in FY 1990, for allocation in

October of this year, will assist the states most in need in this area. However, as we testified last year, we have a long way to go to bring all states to a productive level of automation. Therefore, we would appreciate your consideration of $25 million for ES automation in FY 1991. This investment strategy, over time, will greatly benefit the growing number of applicants and employers requiring our service.

Unemployment Insurance

The President's request for unemployment insurance operations in FY 1991 is based on assumptions that unemployment will be higher than was originally forecast for FY 1990 but lower than the current estimates for this fiscal year. The increase in the request over FY 1990 appropriations reflects higher workloads and normal increases in the cost of operations.

In the past, the accuracy of the Administration's unemployment estimates has not been of as much concern to state administrators as it is now; if estimates were too low, supplemental funds were made available. In the current year, however, states are being asked to handle an additional 289,000 claims per week without additional funds. As you know, it has not been possible to do this without serious disruptions in services to unemployed workers. If the Administration's estimates are again too low, we will be faced with a similar situation next year.

If projections are accurate, and if there is no across-the-board cut, resources for UI will be at about the same level, in terms of the ratio of staff to workload, as when we began the current fiscal year. This level provides fewer permanent/base staff than is reasonable in order for states to maintain a trained group of workers to respond to increased levels of unemployment.

The level of base/permanent staff provided for in the appropriation is expressed in terms of an average number of claims for benefits per week. The President's budget provides for staff to process 1.7 million claims per week; we believe that base/permanent staff should be at least at the level to process 1.9 million claims per week. A higher base staff level would lessen the impact of unanticipated increases in unemployment such as we are experiencing this year.

Labor Market Information

Labor market information is an increasingly important component of the Employment Security System, funded through a variety of programs. Funds for gathering and disseminating key occupational and employment data have been curtailed over the last several years, hampering efforts to create a more competitive labor force. As an example, the Administration's budget request for the Bureau of Labor Statistics includes elimination of the Mass Layoff Statistics program. This $6.1 million program provides an important framework for capturing vital layoff information for the nation and state/local areas, with many states using it for JTPA Title III substate allocations. These mass layoff statistics are particularly needed now, in light of possible defense-related cutbacks and the impact of future free trade agreements.

We also request that FY 1991 funding for labor market information under JTPA Title IV-D be increased from the President's request of $4.2 million to $8.0 million, in order to produce adequate occupational data and analysis for state and substate areas.

Mr. Chairman, thank you for this opportunity to present our views. We would be pleased to respond to any questions that you or other members of the Subcommittee may have concerning these programs.

Senator BURDICK. Thank you.

What would the impact of the fiscal year 1991 funding shortfall be on employment service operations? Will there be any office closings?

Ms. DEROCCO. Undoubtedly, sir, since 1981 with the continued trend toward reduced funding for employment service, our full service offices have dropped from 2,400 in this Nation to 1,700. With an even lower amount appropriated for the 1991 fiscal year, undoubtedly, we would see more full service office closings, a reduction in both the level and the quality of service. And that impacts our ability to put Americans back to productive work.

Senator BURDICK. Thank you.

Ms. DEROCCO. Thank you.

STATEMENT OF SCOTT R. SWIRLING, EXECUTIVE DIRECTOR, NATIONAL FAMILY PLANNING AND REPRODUCTIVE HEALTH ASSOCIATION, INC.

Senator BURDICK. Our next witness will be Scott Swirling, National Family Planning and Reproductive Health Association.

Mr. SWIRLING. Thank you, Senator Burdick. I am Scott Swirling, executive director of the National Family Planning and Reproductive Health Association, the only national organization representing the entire family planning community.

I appreciate the opportunity to submit testimony on behalf of NFPRHA for fiscal year 1991 appropriations for title X of the Public Health Service Act, the National Family Planning Program.

Originally established in 1970, title X is the major Federal preventive health care program dedicated to providing quality, comprehensive family planning and reproductive health care services through a network of over 4,000 clinics. The average title X client is young, female, and has a low or marginal income. For many, particularly poor women, adolescents and women of color, the title X program is the only source of health care readily available.

For fiscal year 1991, the President has requested only $139.1 million for the title X program, the same amount as appropriated for fiscal year 1990. As expected, the administration has also proposed to roll the title X program, for the 10th time in a row, into a State-administered family planning block grant.

The authorization for title X expired in September 1985. For the last 5 years, funding for the program has been carried on continuing resolutions and on the appropriations bill.

Funding for family planning services under title X has been systematically slashed from $162 million in fiscal year 1981 to $135.6 million in fiscal year 1990. Inflationary increases alone, should have brought the current level of title X funding to over $237 million this year.

The erosion of the Family Planning Program over the past decade has had serious consequences. According to DHHS figures, the funding cuts directly attributable to lack of a reauthorized title X statute required the closing of almost 1,000 clinics, 20 percent, and the curtailment of many services.

The network of title X clinics, which is administered by the 10 regional offices, provides the infrastructure for the organized delivery of publicly funded family planning services. Despite the record of success in regional funding, HHS is now proposing to centralize decisionmaking here in Washington and deny local regional officials to make decisions on which agencies should get family planning program grants.

The National Family Planning Association recommends to this committee and to the Congress the following five items for the fiscal year 1991 appropriations.

One, support the title X reauthorization statute as a categorical grant program through the passage of S. 110, and to appropriate at least $171 million for fiscal year 1991 for programs under title X. And we urge rejection, once again, of the administration's block grant for family planning.

We request that Congress appropriate funds for the administration of title X program, in addition to, not combined with, funding for title X service grants, a change that has made the allocation of funding for services very problematic.

Third, to reject in committee report language, the proposal of the administration to reorganize the regional office system.

Four, to provide additional funding for basic research at the National Institute of Child Health and Human Development for new contraceptive methods.

And five, to appropriate $1.3 billion over the President's budget request for Federal funding of AIDS and HIV research prevention and care-related programs, and provide services to women, adolescents, and children with AIDS.

Last year, $10 million was put into the Senate bill for pediatric AIDS counseling and counseling and outreach through family planning programs. We urge that that be put back in this year.

PREPARED STATEMENT

In conclusion, despite serious administration attempts in the past decade to undermine it, the successes of the national title X program cannot be ignored. They are an endorsement for the reauthorization of title X and for the appropriation of $171 million for fiscal year 1991. Adequate funding of family planning and contraceptive research programs will send a strong message that Congress values reproductive health care as a high priority, even in these times of fiscal constraint.

Thank you, Senator. I will answer any questions you might have.

Senator Burdick. Thank you for your testimony.

Mr. Swirling. Thank you.

[The statement follows:]

STATEMENT OF SCOTT R. SWIRLING

Mr. Chairman and Members of the Subcommittee:

I am Scott R. Swirling, Executive Director of the National Family Planning and Reproductive Health Association (NFPRHA). I appreciate the opportunity to submit testimony on behalf of NFPRHA on fiscal year 1991 appropriations for Title X of the Public Health Service (PHS) Act, "Population Research and Voluntary Family Planning Programs and other programs under the PHS.

NFPRHA is a non-profit membership organization, established to improve and expand the delivery of voluntary family planning and reproductive health care services nationwide. As the only national organization representing the entire family planning community, NFPRHA represents almost all agencies funded under the national Title X family planning program including: state-county-local health departments; hospital-based clinics; Planned Parenthood Federation of America Affiliates; family planning councils; independent free-standing clinics; and individual providers, researchers, and consumers. Our members provide reproductive health care services to nearly five million women, men and adolescents.

TITLE X - A PREVENTIVE PUBLIC HEALTH PROGRAM

Originally established in 1970 with the enactment of P.L. 91-572, the "Family Planning Services and Population Research Act," primarily to increase access to contraceptive services to reduce the number of unintended pregnancies in this country, especially among poor women and adolescents, Title X is the major federal preventive health care program dedicated to providing quality comprehensive family planning and reproductive health care services through a network of over 4,000 clinics. The average Title X client is young, female, and has a low or marginal income. For many, particularly poor women, adolescents and people of color, the Title X program is the only source of health care readily available. Although the program has not been reauthorized since 1985, each year Congress has demonstrated support for Title X by rejecting the Administration's proposal to replace the national Title X program with a block grant "state administered family planning program." For FY 1991, President Bush has requested only $139.1 million for the Title X program, the same amount that was appropriated in FY 1990, although only $135.6 million of that total would be available for services grants and contracts. As expected, the Administration again proposed to roll the Title X program into a state block grant program.

The authorization of the Title X statute expired on September 30, 1985. For the last five years, the Title X appropriation has been carried on a series of continuing resolutions and the FY 1989 and FY 1990 DHHS appropriations acts. The result has been a reduction in the funds appropriated and an inability of the program to institute needed statutory reforms. Despite the overwhelming evidence for the need to expand and to improve the delivery of family planning services and to increase federal support, funding for the Title X program has not increased in real dollars since 1973. And, funding for family planning services under Title X has been systematically slashed from $162 million in FY 1981 to $135.6 million in FY 1990. Inflationary increases alone should have brought the current level of Title X funding to over $237 million this year.

The erosion of the family planning program over the past decade has had serious consequences. According to DHHS figures, the funding cuts directly attributable to the lack of a reauthorized Title X statute required the closing of almost 1,000 clinics and the curtailment of many services. The federal government's investment in family planning and reproductive health care must be matched by a much stronger commitment.

In addition to providing contraceptive information and services, this program serves an array of purposes, among them the upgrading of reproductive health, the prevention of government dependency, and the improvement of the health and economic well being of women, children, and families. Typically, Title X programs provide: physical examinations; contraceptive information and services; Pap smears; screening and treatment for sexually transmitted diseases (STDs); AIDS/HIV testing and counseling; cancer screening; hemoglobin tests; urinalysis; pregnancy and infertility testing; parent/teen communication; maternal and child health; problem pregnancies; related medical problems; services for men, such as counseling, education and the provision of condoms; special teen clinics; adolescent health education; and community education programs.

As mentioned in NFPRHA's recently released report, The 1980's: Decade of Disaster For Family Planning, in which we challenge the Bush Administration to provide the needed leadership to ensure that access to family planning and reproductive health care is a national priority, currently 3.5 million low income women and 1.5 million adolescents annually are dependent on Title X clinic services. It is estimated that an additional 5.3 million poor women and 3.4 million teenage girls are in need of reproductive health care but cannot obtain services. Although millions of unintended pregnancies are averted each year as a direct result of services provided by Title X clinics, the increase in the number of unintended pregnancies and abortions is staggering. Over 50 percent of the six million pregnancies yearly in this country are unintended, with 1.1 million of those pregnancies occurring among teenagers. Eighty percent of all teenage pregnancies are unintended and more than 1.5 million abortions occur each year, over 400,000 to teenagers. Given these alarming facts, it is clear that the need for the Title X program, the only proven federal health care services program aimed at preventing unintended pregnancy and reducing the incidence of abortion, is greater than ever. Furthermore, enhanced support for such a broad range of services for a growing population of reproductive health care consumers is critical to the individual receiving services and to society. In a recently published study by The Alan Guttmacher Institute on Public-Sector Savings Resulting from Expenditures for Contraceptive Services, researchers conclude that every $1 spent on contraceptive services, saves an average of $4.40. Publicly-funded planning services enable women to prevent unintended pregnancies, births and abortions and that federal funds allocated to support the provision of services are small compared with the large savings that result. The study also finds that through the expansion and improvement of the provision of contraceptive services, reproductive health care consumers could more effectively reduce the incidence of unintended pregnancies and abortions. As the Center for Population Options pointed out in its 1986 study of public costs of teenage childbearing, "Not only is teenage childbearing a threat to the health and welfare of the mother and child, but adolescent pregnancy contributes to such societal problems as poverty, unemployment, family disintegration, juvenile crime, school dropouts and child abuse."

The network of Title X clinics, which is currently administered by ten regional offices, provides the infrastructure for the organized delivery of publicly-funded family planning services. Through regional administration of the Title X grant program, federal decisionmakers and state-county-local providers are able to work effectively and cooperatively in determining the allocation of grants and the provision of services based on the diverse needs of the populations served by this program. Nevertheless, officials at the Department of Health and Human Services (DHHS) are considering a proposal to reorganize PHS regional offices and to centralize family planning grantmaking in the Office of Population Affairs in Washington, D.C. Any reorganization of the Title X regional offices would have a devastating impact on the Title X program and would seriously undermine its effectiveness.

As the Senate Labor and Human Resources Committee stated last year in its report accompanying S. 110, the "Family Planning Amendments of 1989, "the Secretary is directed to make each grant decision on the basis of the types of services needed within a given region," and that this is "best determined by officials located in that region." The Committee "strongly encourages the Secretary to maintain the current system of regional decisionmaking for the Title X family planning services grants." This report language was followed by last year's conference report accompanying P.L. 101-166, the FY 1990 appropriations bill for DHHS, in which Congress specifically instructed the Department not to initiate a reorganization of the PHS regional offices without first obtaining approval through a reprogramming request.

CONTRACEPTIVE RESEARCH

There is increasing evidence that the United States lags far behind many other countries in making available new, safe, and effective contraceptive methods. According to a two-year study, Developing New Contraceptives: Obstacles and Opportunities, released last month by the National Research Council's Committee on Contraceptive Development of the National Academy of Sciences, "Currently available contraceptive methods are not well suited to the religious, social, economic, or health circumstances of many Americans." The study noted that women in other countries have access to an array of contraceptive techniques that are easier to use and more reliable. In addition, the study concluded that men, teenagers, women over 35, and breastfeeding mothers urgently need better birth control methods. The committee also found that new methods could become available if there were more support for their development. Among those methods most promising are long-acting implants, contraceptive vaccines, new spermicidal agents with antiviral properties, reversible male and female sterilization, and new methods for ovulation prediction and self-detection. Yet, no newly developed methods of birth control have been approved in this country in the last two decades. The committee emphatically recommends that the federal government should increase funding for contraceptive research and development and incorporate policies that ensure long-term stability for priority research projects. Furthermore, the committee recommends that the Food and Drug Administration revise its procedures for evaluating and approving new contraceptive products.

With only a handful of private foundations and one pharmaceutical company supporting basic research in the reproductive sciences, the bulk of research is conducted by the National Institute of Child Health and Human Development (NICHD) of the National Institutes of Health. NICHD's Center for Population Research oversees research and development in the area of contraception and reproductive sciences. Although the Administration has requested a slight increase of $4.8 million (including AIDS) to $132.4 million for population research in FY 1991, this is considerably low given the difficulty in maintaining current levels of grant awards and making new awards. NICHD is also the leading federal research agency to support research on maternal and child health. For FY 1991, the Administration has requested $247.2 million (including AIDS), only $9.2 million over the FY 1990 level. The low funding rate of research grant projects and insufficient funds for the continuation and the expansion of vital research initiatives has created enormous budgetary problems for the Institute, especially with respect to research priorities including: low birth-weight/infant mortality; teenage pregnancy; contraception; and fertility.

AIDS

Support for AIDS research, prevention and services remains a high priority for reproductive health care providers. In particular, we are very concerned about federal support for programs to provide testing and counseling services and to assure successful interventions in the spread of AIDS and HIV infection, especially for adolescents at risk, pregnant women, children, and people of color. It is estimated that nearly 3,500 children will have AIDS by 1991 and approximately 20,000 will be HIV-infected. Several hundred teenagers are reported to have AIDS. However, these numbers mask the true incidence of HIV infection in adolescents. The estimated 211,736 AIDS cases among people in their twenties may serve as an indicator of the prevalence of the virus among adolescents. Since HIV infection among teenagers is most often transmitted through unprotected sexual activity, the rate of heterosexual transmission among adolescents is double that of adults. The provision of condoms through family planning services to prevent the spread of AIDS must be accessible for at risk adolescents. There is also a higher prevalence of HIV infection among minority youth and people of color in low-income communities. Typically, these populations lack access to health care services and are often not detected and treated.

There is also a serious crisis occurring with the spread of sexually transmitted diseases (STDs). Family planning and reproductive health care providers are increasingly screening and treating patients for STDs. Yet, federal support for the provision of these services has not increased.

FISCAL YEAR 1991 APPROPRIATIONS RECOMMENDATIONS

1. Support the reauthorization of the Title X statute as a categorical grant program through the passage of the Kennedy bill, S.110. The reauthorization of the categorical Title X program is essential to ensure long-term stability in the provision of the most effective range of family planning methods and reproductive health care services for poor women, adolescents, and people of color. Appropriate at least $171 million for FY 1991 for programs under Title X as requested in the Kennedy Title X reauthorization bill, S. 110. We urge Congress to reject for the tenth time the Administration's funding request and proposal to replace Title X with a block grant state administered family planning program.

2. Appropriate funds for the administration of the Title X program by the Office of Population Affairs in addition to, and in a separate line item from, the appropriation for family planning program activities, specifically services grants and contracts. Furthermore, we suggest that a clear delineation between funds for program management/program support and family planning services be included in future committee and conference reports.

3. Specifically reject in committee report language the proposal by the Administration to reorganize the PHS regional offices through centralization. We recommend that the Subcommittee include committee and conference report language in this year's appropriations bill to prohibit the Administration from centralizing the grantmaking authority for Title X through the reorganization of the ten regional offices.

4. Provide additional funding for basic research at NICHD on new contraceptive methods to be made available to individuals at risk for unintended pregnancy and abortion. In addition, we recommend that the Subcommittee appropriate funds to support the establishment of three new research centers on contraception and two new centers on infertility, as proposed in the Harkin/Packwood bill, S. 2215, the "Contraceptive and Infertility Research Centers Act of 1990, which authorizes $20 million for FY 1991 and additional funds for subsequent years through FY 1995. Further, we encourage the Subcommittee to seriously consider recommendations in the National Research Council's recent study on Developing New Contraceptives: Obstacles and Opportunities.

5. Appropriate $1.3 billion over the President's budget request for FY 1991 for federal funding of AIDS/HIV research, prevention and care related programs that provide services to women, adolescents and children with AIDS. Specifically, we recommend that

the Subcommittee appropriate $10 million for grants to the network of Title X clinics for outreach, counseling and family planning services for women who are HIV positive or at risk of infection.

CONCLUSION

Despite serious administration attempts in the past decade to undermine it, the successes of the national Title X family planning program cannot be ignored. They are an endorsement for the reauthorization of Title X and for NFPRHA's request that this Subcommittee and Congress approve an appropriation for Title X of $171 million for fiscal year 1991. Adequate funding of family planning and contraceptive research programs will send a strong message that Congress values reproductive health care as a high priority, even in these times of fiscal constraint.

Thank you very much for your consideration of NFPRHA's requests. I look forward to working with the Subcommittee in the future.

STATEMENT OF CHARLES O. CRANFORD, EXECUTIVE DIRECTOR, ARKANSAS AHEC PROGRAM, NATIONAL AREA HEALTH EDUCATION CENTERS PROGRAM

Senator BURDICK. Our next witness will be Dr. Charles Cranford, director of Arkansas Area Health Education Centers, AHEC Program.

Dr. CRANFORD. Thank you, Senator Burdick. I am Dr. Charles Cranford. I am the executive director of the Arkansas Area Health Education Centers or AHEC, as we call it.

I am here today on behalf of AHEC projects on 26 States that are receiving Federal funding through the Health Resources and Services Administration. AHEC projects receiving Federal funding include, but are not limited to Arizona, Washington, Nevada, Texas, Oklahoma, Kentucky, South Dakota, Georgia, Florida, Louisiana, Maine, as well as my State of Arkansas. All sections of the Nation have AHEC programs.

As we have indicated in previous appearances, we appreciate the support that we have received through the years from this subcommittee. We believe it is essential that the national AHEC program continue, and we urge the full appropriation of $20 million authorized for the fiscal year that begins October 1, 1990. We also support the full appropriation of $12 million for the new health education and training centers within the AHEC authority.

Throughout the United States, we continue to attack the problem of maldistribution of physicians and other health practitioners in rural and inner-city areas. I am happy to report that we are making important progress. In my State of Arkansas, for example, 50 of our 75 counties have received family practice physicians trained in the AHEC program.

Many rural and inner-city areas around the United States still do not have enough physicians, nurses, and other health professionals. Particularly distressing is the fact that this problem persists in a time when we are hearing a lot of talk about a potential over supply of physicians in general. The simple truth is that young physicians do not tend to set up practice in rural or inner-city areas unless they receive a lot of special attention, and AHEC tries to provide that attention.

The AHEC program has evolved into an effective partnership involving the Federal Government, State governments, local governments, health science schools, community hospitals, and health practitioners. We have all types of people from the public and private sectors working together in pursuit of a common public policy objective.

For example, in Arkansas, over 500 of our State's private physicians regularly teach through our AHEC program. Our program enables students and medical residents at health science schools to take a portion of their clinical training at community hospitals and health centers, an arrangement that ends up benefiting everyone.

Major efforts have been undertaken to develop interdisciplinary educational programs in community settings in the areas of aging, health promotion and disease prevention, AIDS, health services management, cost containment, mental health, and quality assurance.

The national AHEC program has proved to have been a wise investment for the Federal Government. Federal spending has led to the establishment of AHEC's for 32 States, and has spurred State and local governments into spending hundreds of millions of dollars for AHEC programs in response to the Federal catalyst. This year, for example, the State of Arkansas spends more than $10 for every $1 of Federal support received for AHEC.

PREPARED STATEMENT

We hope that in fiscal year 1991 budget, Congress will maintain its commitment to a program aimed at ending the maldistribution of health practitioners in rural and inner-city areas.

Thank you again for the opportunity to appear.

[The statement follows:]

STATEMENT OF CHARLES O. CRANFORD

MR. CHAIRMAN AND MEMBERS OF THE SUBCOMMITTEE, I AM DR. CHARLES CRANFORD, AND I AM THE EXECUTIVE DIRECTOR OF THE ARKANSAS AREA HEALTH EDUCATION CENTERS PROGRAM, OR AHEC, AS WE CALL IT.

I AM HERE TODAY ON BEHALF OF 24 AHEC PROJECTS IN 26 STATES THAT ARE RECEIVING FEDERAL AHEC FUNDING THROUGH THE HEALTH RESOURCES AND SERVICES ADMINISTRATION. AHEC PROJECTS RECEIVING FEDERAL FUNDING INCLUDE ARIZONA, WASHINGTON, NEVADA, TEXAS, OKLAHOMA, KENTUCKY, GEORGIA, FLORIDA, LOUISIANA, MAINE, AS WELL AS MY STATE OF ARKANSAS. ALL SECTIONS OF THE NATION HAVE AHEC PROGRAMS.

AS WE HAVE INDICATED IN PREVIOUS APPEARANCES, WE APPRECIATE THE SUPPORT THAT WE HAVE RECEIVED THROUGH THE YEARS FROM YOU AND FROM THIS SUBCOMMITTEE. WE BELIEVE IT IS ESSENTIAL THAT THE NATIONAL AHEC PROGRAM CONTINUE. WE URGE THE FULL APPROPRIATION OF $20 MILLION AUTHORIZED FOR THE FISCAL YEAR THAT BEGINS OCTOBER 1, 1990. WE ALSO SUPPORT THE FULL APPROPRIATION OF $12 MILLION FOR THE NEW HEALTH EDUCATION AND TRAINING CENTERS WITHIN THE AHEC AUTHORITY.

THROUGHOUT THE UNITED STATES WE CONTINUE TO ATTACK THE PROBLEM THAT LED TO THE ESTABLISHMENT OF THE NATIONAL AHEC PROGRAM--THAT PROBLEM BEING THE MALDISTRIBUTION OF PHYSICIANS AND OTHER HEALTH PRACTITIONERS IN RURAL AND INNER CITY AREAS. I AM HAPPY TO REPORT, MR CHAIRMAN, THAT WE ARE MAKING IMPORTANT PROGRESS. IN MY STATE OF ARKANSAS, FOR EXAMPLE, 50 OF OUR 75 COUNTIES HAVE RECEIVED FAMILY PRACTICE PHYSICIANS TRAINED IN THE AHEC. A RECENT NATIONAL STUDY DEMONSTRATED THAT FOR THE ORIGINAL ELEVEN AHEC PROJECTS FUNDED IN 1972, THE IMPROVEMENT IN THE RATIO OF PRIMARY CARE PHYSICIANS TO POPULATION IN RURAL COUNTIES IS THREE TO FIVE PERCENT BETTER THAN THOSE RURAL COUNTIES HAVING NO AHEC ACTIVITIES.

ALTHOUGH MANY AMERICANS NOW ENJOY A STANDARD OF HEALTH CARE THAT WOULD HAVE SEEMED UNIMAGINABLE TWO DECADES AGO, MUCH REMAINS TO BE DONE. MANY RURAL AND INNER CITY AREAS AROUND THE UNITED

STATES STILL DO NOT HAVE ENOUGH PHYSICIANS, NURSES AND OTHER HEALTH PROFESSIONALS. PARTICULARLY DISTRESSING IS THE FACT THAT THIS PROBLEM PERSISTS AT A TIME WHEN WE ARE HEARING A LOT OF TALK ABOUT A POTENTIAL OVERSUPPLY OF PHYSICIANS IN GENERAL. THE SIMPLE TRUTH IS THAT YOUNG PHYSICIANS DO NOT TEND TO SET UP PRACTICE IN RURAL OR INNER CITY AREAS UNLESS THEY RECEIVE A LOT OF SPECIAL ATTENTION. AHEC PROVIDES THAT ATTENTION.

THE MALDISTRIBUTION OF HEALTH PROFESSIONALS IS A TERRIBLY DIFFICULT PROBLEM, MR. CHAIRMAN. THAT WAS SOMETHING THAT WE IN THE HEALTH EDUCATION COMMUNITY RECOGNIZED AT THE TIME THAT THE AHEC CONCEPT WAS BEING DEVELOPED. THE CONGRESS RECOGNIZED IT, TOO, AND PASSED LEGISLATION THAT PROVIDED FEDERAL FUNDS FOR THE NATIONAL AHEC PROGRAM. EVERYONE INVOLVED KNEW WE WERE TALKING ABOUT A TREMENDOUS EFFORT THAT WOULD NEED TO BE MEASURED IN TERMS OF DECADES, NOT YEARS.

THE AHEC PROGRAM HAS EVOLVED INTO AN EFFECTIVE PARTNERSHIP INVOLVING THE FEDERAL GOVERNMENT, STATE GOVERNMENTS, LOCAL GOVERNMENTS, HEALTH SCIENCE SCHOOLS, COMMUNITY HOSPITALS AND HEALTH PRACTITIONERS. THE PARTNERSHIP INVOLVES THE OTHER PRIMARY CARE INITIATIVES OF THE FEDERAL GOVERNMENT, AS WELL. THAT KIND OF COOPERATION SEEMS TO HAPPEN ALL TOO RARELY IN OUR SOCIETY, AND WE WHO ARE ASSOCIATED WITH AHEC FEEL MOST FORTUNATE. WE HAVE ALL TYPES OF PEOPLE FROM THE PUBLIC AND PRIVATE SECTORS WORKING TOGETHER IN PURSUIT OF A COMMON PUBLIC POLICY OBJECTIVE. FOR EXAMPLE, IN ARKANSAS, OVER 500 OF OUR STATE'S PRIVATE PHYSICIANS REGULARLY TEACH THROUGH OUR AHEC PROGRAM.

THE AHEC PROGRAMS ENABLE STUDENTS AND MEDICAL RESIDENTS AT HEALTH SCIENCE SCHOOLS TO TAKE A PORTION OF THEIR CLINICAL TRAINING AT COMMUNITY HOSPITALS AND HEALTH CENTERS--AN ARRANGEMENT THAT ENDS UP BENEFITING EVERYONE. THE STUDENTS AND THE RESIDENTS RECEIVE AN EXPOSURE TO PRACTICING PHYSICIANS IN A COMMUNITY SETTING--SOMETHING THEY MIGHT NOT HAVE HAD OTHERWISE. THE LOCAL AGENCIES GET THE SERVICES OF HIGHLY QUALIFIED HEALTH

PERSONNEL AND THE PEOPLE OF THE COMMUNITY HAVE ACCESS TO BETTER HEALTH CARE.

THE HOPE, OF COURSE, IS THAT SOME OF THE YOUNG HEALTH PROFESSIONALS WHO PARTICIPATE IN THIS COMMUNITY-BASED PROGRAM WILL DECIDE AFTER COMPLETING THEIR EDUCATION TO PRACTICE IN RURAL OR INNER CITY AREAS--THE AREAS WHERE HELP IS DESPERATELY NEEDED. IN ARKANSAS, 82 PERCENT OF THE FAMILY PRACTICE PHYSICIANS TRAINED IN AHEC'S HAVE REMAINED IN THE STATE, AND 37 PERCENT OF THOSE HAVE LOCATED IN TOWNS OF FEWER THAN 10,000 PERSONS. MOREOVER, THIS PERCENTAGE IS INCREASING AND HAS BEEN 50 PERCENT DURING THE LAST THREE YEARS.

THE AHEC PROGRAMS ALSO WORK WITH HEALTH SCIENCE SCHOOLS TO OFFER CONTINUING EDUCATION AND TECHNICAL ASSISTANCE TO PRACTICING HEALTH PROFESSIONALS THROUGHOUT THE STATE. THIS SERVICE NOT ONLY HELPS COMMUNITY-BASED PROFESSIONALS FEEL LESS ISOLATED BUT ALSO ASSURES THEM THAT THEY CAN KEEP UP-TO-DATE EVEN IF THEY PRACTICE FAR FROM THE MAJOR MEDICAL CENTERS.

I AM HAPPY TO ALSO REPORT THAT AHEC'S AROUND THE NATION HAVE BEEN SUCCESSFUL IN ADAPTING PROGRAMMING TO MEET CHANGING COMMUNITY NEEDS. MAJOR EFFORTS HAVE BEEN UNDERTAKEN TO DEVELOP INTERDISCIPLINARY EDUCATIONAL PROGRAMS IN COMMUNITY SETTINGS IN THE AREAS OF AGING, HEALTH PROMOTION AND DISEASE PREVENTION, AIDS, HEALTH SERVICES MANAGEMENT, COST CONTAINMENT, MENTAL HEALTH, AND QUALITY ASSURANCE.

MR. CHAIRMAN, THE NATIONAL AHEC PROGRAM HAS PROVEN TO HAVE BEEN A WISE INVESTMENT FOR THE FEDERAL GOVERNMENT. SINCE 1972, FEDERAL FUNDING FOR AHEC'S NATIONWIDE HAS TOTALED ABOUT THE SAME AMOUNT THAT THE U.S. OBLIGATES FOR THE HEALTH CARE FINANCING ADMINISTRATION EVERY TWO TO THREE DAYS. THAT MODEST AMOUNT OF FEDERAL SPENDING HAD LED TO THE ESTABLISHMENT OF AHEC'S FOR 32 STATES, 24 OF WHICH ARE STILL RECEIVING FEDERAL FUNDS, AND IT HAS SPURRED STATE AND LOCAL GOVERNMENTS INTO SPENDING HUNDREDS OF MILLIONS OF DOLLARS FOR AHEC PROGRAMS IN RESPONSE TO THE FEDERAL CATALYST. THIS YEAR, FOR EXAMPLE, THE STATE OF ARKANSAS SPENDS

MORE THAN $10 FOR EVERY DOLLAR OF FEDERAL SUPPORT RECEIVED FOR AHEC.

THE NATIONAL AHEC PROGRAM DEMONSTRATES OUR GOVERNMENT WORKING AT ITS BEST. WE INVITE THE SUBCOMMITTEE TO REVIEW THE STRONG ENDORSEMENTS OF THE AHEC PROGRAM CONTAINED IN THE FOLLOWING STUDIES:

1. THE 1978 REPORT OF THE GENERAL ACCOUNTING OFFICE;
2. THE 1978 REPORT OF THE HOUSE APPROPRIATIONS COMMITTEE;
3. THE 1976 AND 1979 REPORTS OF THE CARNEGIE COUNCIL;
4. THE 1980 REPORT TO THE CONGRESS BY THE SECRETARY OF H.E.W.;
5. THE 1980 GMENAC REPORT;
   AND
6. THE 1990 REPORT OF THE AMERICAN INSTITUTE FOR RESEARCH COMMISSIONED BY THE HEALTH RESOURCES AND SERVICES ADMINISTRATION.

WE IN AHEC HOPE THAT, IN THE FISCAL YEAR 1991 BUDGET, THE CONGRESS WILL MAINTAIN ITS COMMITMENT TO A PROGRAM AIMED AT ENDING THE MALDISTRIBUTION OF PHYSICIANS AND HEALTH PRACTITIONERS IN RURAL AND INNER-CITY AREAS. THIS COMMITMENT ALLOWS FOR FUNDING OF STATEWIDE AHEC'S, REGIONAL AHEC'S, AHEC SPECIAL INITIATIVES, INFANT MORTALITY, AND HIGH IMPACT AREAS. THE UNITED STATES, MR. CHAIRMAN, CANNOT AFFORD TO BE WITHOUT THIS PROGRAM. THANK YOU AGAIN FOR THE OPPORTUNITY TO APPEAR HERE TODAY.

WE IN THE AHEC PROGRAM LOOK FORWARD TO CONTINUING TO WORK WITH THE CONGRESS IN THE INTEREST OF ENSURING ACCESS TO PROPER HEALTH CARE FOR ALL AMERICANS.

Senator **Burdick**. Thank you.

Can you tell us how the AHEC program has impacted minority health in your State? I am interested in knowing this since the President's budget request funded some minority health programs, but it does not fund either AHEC or other health education centers.

Dr. **Cranford**. We have AHEC programs that address minority needs, population needs, in the areas that border Mexico, which have high Hispanic populations. We have AHEC's that address needs in those areas where there are high native American populations, and in areas where there are high black populations.

We are taking students and residents from medical schools, and we are giving them training experiences, clinical experiences, within those areas in an attempt to encourage them to practice in areas with high minority populations when they finish their schooling.

We, as an adjunct to our training programs, deliver a lot of health care services. We work with community health centers. We provide manpower through those centers when they are not supplied by the National Health Service Corps. And in a number of ways like that, we are attempting to do what we can to address the great needs that exist among minority populations.

STATEMENT OF DAVID W. ROLKA, COMMISSIONER, PENNSYLVANIA PUBLIC UTILITY COMMISSION ON BEHALF OF THE NATIONAL ASSOCIATION OF REGULATORY UTILITY COMMISSIONERS, INC.

Senator **Burdick**. The next witness is David W. Rolka, the National Association of Regulatory Utility Commissioners. Welcome to the committee.

Mr. **Rolka**. Thank you, Senator. Good morning Senator and remaining staff members. My name is Dave Rolka. I am a commissioner of the Pennsylvania Public Utility Commission and I am here representing the National Association of Utility Commissioners.

We appreciate the opportunity to address this committee, to express our strong, continuing support for the extremely important program. NARUC urges you to expeditiously consider and promptly approve the imperative authorization of the LIHEAP on a long-term basis and to appropriate fiscal year 1991 LIHEAP funds closer to the authorized amount.

LIHEAP prevents health and life-threatening hardships for our neediest and most vulnerable citizens. LIHEAP is a need-based, income supplement program serving only the very needy households, of which nearly 60 percent have annual incomes of less than $6,000. More than one-half of the recipient households are working poor or elderly.

Earlier, it was commented that although some States have not earmarked their general fund revenues toward LIHEAP-type programs, I would like to point out that our Pennsylvania Public Utility Commission, as have, I understand some other States, earmarked some funds that would otherwise have been directed into fines and redirected those funds toward energy assistance programs like the LIHEAP Program. So, money that normally would have gone into the State general funds, had it been reappropriated back out, has never gone there in the first place, but it has gone directly to the programs.

Private assistance is too small and too stretched to fill the growing gap left by the shrinking Federal LIHEAP assistance. Utility disconnection moratoria give winter protection in some States, but many millions of families have inadequate protection because they use fuel oil, propane or other unregulated fuels or are in States without winter protections. The existence of such moratoriums, in no way provides a complete or meaningful solution to the problem. On the contrary, the pattern of the timing during the bulk of the utility terminations occur in Pennsylvania merely serve to underscore the year-round nature of the problem.

This year, 43 percent of Philadelphia's fire-related deaths have been linked to utility shut offs. Households that cannot raise sufficient funds to arrange for restoration of utility services in time for the next heating season, face serious and chilling choices. This bitter reality was amply demonstrated by a series of well publicized tragedies which occurred around the country during December 1989 and January 1990 involving the absence of home heating or the use of potentially dangerous alternatives.

In some of the cases that were mentioned earlier in Philadelphia involved people whose utility services have been terminated for several years. There are vast numbers of potential tragedies waiting to occur, where still-occupied homes are totally without heat and an even larger number make use of potentially dangerous heating sources, like those involved in the recent fires.

PREPARED STATEMENT

The preventative role played by LIHEAP in preserving the housing of low-income households and avoiding more serious consequences of property abandoned cannot be overlooked.

NARUC implores the committee to ensure that there will be room in the Federal budget for adequate LIHEAP funding so the poor will at least have warmth in their poverty. Thank you, Senator.

[The statement follows:]

STATEMENT OF DAVID W. ROLKA

Mr. Chairman and Members of the Subcommittee:

My name is David W. Rolka. I am a Commissioner of the Pennsylvania Public Utility Commission and I am appearing on behalf of the National Association of Regulatory Utility Commissioners, or NARUC.

The NARUC is a quasi-governmental, nonprofit organization founded in 1989. Within our membership are the governmental agencies of the 50 states, the District of Columbia, Puerto Rico, and the Virgin Islands, engaged in the regulation of utilities and carriers. We are charged with the protection of the public interest, and it is for this reason that we are supporting restored funding for the Low Income Home Energy Assistance Program (LIHEAP).

We appreciate the opportunity to address this committee to express our strong continuing support for this extremely important program. NARUC urges you to expeditiously consider and promptly approve the imperative authorization of LIHEAP on a long-term basis, and to appropriate FY-1991 LIHEAP funds closer to the authorized amount. On February 28, 1990, the Executive Committee of NARUC reaffirmed its support for LIHEAP at its Winter Meeting in Washington, D.C. A copy of our resolution is attached to this testimony.

We believe that LIHEAP has already contributed more than its share to reducing the nation's deficit. LIHEAP still serves less than half of the eligible population, and grant levels are sufficient to cover only a small portion of home heating or cooling costs. Over the past four years, the program has suffered a 35% cut -- from $2.01 billion in FY-1986 to $1.393 billion in FY-1990. Close to one million poor households were eliminated from the program just in the last two fiscal years.

President Bush's FY-1991 budget proposal would cut LIHEAP another $343 million or 24%, which could eliminate additional hundreds of thousands of households from the program. It would be a terrible and shameful act for this nation to shift this additional burden onto the backs of the poor when they cannot even pay their current energy bills. This comes at a time when residential prices for primary heating fuels are rising and States and localities have been unable to adequately deal with even normal winter weather needs, much less the cold weather emergencies and rapid price increases evidenced in December 1989.

It has been repeatedly observed that the typical low-income household spends about 14% of its income on energy, which is four times the percentage paid by middle income households. For the poorest of the poor, the burden is even higher. The real income of poor families has not risen as fast as inflation, causing a dramatic drop in their buying power.

While some may retain the stereotypical notion that the Nation's nearly six million LIHEAP recipient households are "undeserving" or "deadbeats", nothing could be further from the truth. LIHEAP prevents health and life-threatening hardships for our neediest and most vulnerable citizens. LIHEAP is a needs-based income supplement program serving only very needy households, of which nearly 60% have annual incomes of less than $6,000, and more than half of the recipient households are working poor or elderly. It is more true today than ever that millions of poor households still must choose between eating and heating.

Both Congress and the Administration have been distracted by the phantom of oil overcharge dollars, which are now virtually depleted. Moreover, those funds were designed to make up for past injuries and were to supplement not supplant, existing federal and State resources.

As State utility regulators, we continually face situations throughout the country where consumers unable to pay their bills are shut off -- despite the existence of LIHEAP, private fuel funds, weatherization programs and the various payment plans and customer assistance programs offered by utility companies. Over 50,000 residential terminations of regulated gas and electric service took place in Pennsylvania during 1989.

Private assistance is too small and too stretched to fill the growing gap left by shrinking federal LIHEAP assistance. Utility disconnection moratoria give winter protection in some States, but many millions of families have inadequate protection because they use fuel oil, propane and other unregulated fuels, or are in States without winter protections. The existence of such moratoria in no way provides a complete or meaningful solution for the problem. On the contrary, the pattern of the timing during which the bulk of utility terminations occur in Pennsylvania merely serves to underscore the year-round nature of the problem. Many warm weather shut-offs stem from unpaid bills from the prior heating season; yet when they occur, the LIHEAP program is closed down, leaving only private fuel funds to attempt to respond to these needs.

Households that cannot raise sufficient funds to arrange for restoration of utility service in time for the next heating season face serious and chilling choices. This bitter reality was amply demonstrated by a series of well-publicized tragedies which occurred around the country during December 1989 and January 1990, involving the absence of home heating or the use of potentially dangerous alternatives. Three of the cases occurred in Philadelphia, and resulted in the deaths of three adults (two of them elderly) and five young children (only one of whom was over the age of three) in the space of just a few weeks.[1]

There are vast numbers of potential tragedies waiting to occur, where still-occupied homes are totally without any heating source whatsoever, and an even larger number make use of potentially dangerous heating sources, like those involved in the recent fires. The preventative role played by LIHEAP in preserving the housing of low-income households and avoiding the more serious consequences of property abandonment -- for society as a whole -- cannot be overlooked. Based on data provided by the City of Philadelphia's Low Income Weatherization Program and its Cold Weather Heater Repair Hotline Program, it is estimated that some 25,000 low-income households in Philadelphia alone have abandoned the use of their central heating system and are therefore relying on space heaters or ranges to heat their homes. The clear implications are that the amount of federal funding made available for LIHEAP is far from adequate to meet the need.

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[1] The two senior citizens froze to death in a home which used oil heat. Their oil tank was empty and they had no telephone with which to reach out for help. Obviously, winter moratoria offer no protection whatsoever to the 30% of low-income households who heat with unregulated fuels; LIHEAP is their only lifeline.

In the other two situations, the electric and/or gas service had previously been terminated for unpaid bills, and the potentially hazardous alternatives that too many low-income households depend upon as their only course of survival were in use; candles, kerosene space heaters and illegal connections to the electrical service of a neighboring property.

It is wrong to think that LIHEAP benefits are simply another form of welfare for those already receiving other traditional forms of public assistance. Approximately 65% receive no other traditional public assistance. Many of the LIHEAP recipients are the working poor. While many of us think that the energy crisis is over, for the poor it continues. NARUC implores this subcommittee to insure that there will be room in the federal budget for adequate LIHEAP funding so the poor will at least have warmth in their poverty. Thank you.

Resolution Regarding Reauthorization and Appropriations for the Low Income Home Energy Assistance Program

WHEREAS, *The National Association of Regulatory Utility Commissioners (NARUC, recognizes the critical role that the Low Income Home Energy Assistance Program (LIHEAP) has played in providing assistance to millions of households in meeting their energy needs; and*

WHEREAS, *The Executive Committee of the NARUC adopted a resolution urging Congress to increase the funding for LIHEAP and the Weatherization Assistance Program at its 1989 Winter Meeting in Washington, D.C.; and*

WHEREAS, *LIHEAP is a needs-based income supplement program serving only very needy households, of which nearly 60 percent have annual income under $6,000; and*

WHEREAS, *More than one-half of the households that receive LIHEAP are the working poor or elderly, and most LIHEAP households do not receive any other type of public assistance; and*

WHEREAS, *LIHEAP funds last year helped to provide heating assistance, emergency energy assistance to those in urgent life-threatening situations, and cooling assistance to approximately 6 million households (down from 7.1 million in 1981), and also was used for weatherization of low-income households; and*

WHEREAS, *The average LIHEAP-eligible household spends about 14 percent of its income on energy, which is FOUR times that paid by middle income households, and the real income of poor families has not risen as fast as inflation, thus causing a dramatic drop in their buying power; and*

WHEREAS, *The program has suffered a 35 percent cut over the past four years (from $2.01 billion in FY 1986 to $1.393 billion in FY 1990 despite the obvious need to increase energy payment assistance, and those cuts eliminated close to one million poor households from the program while LIHEAP benefits were also reduced; and*

WHEREAS, *Utility commissions find that inadequate funding and recent cuts to LIHEAP have contributed to great hardship to elderly and low-income households, resulting in thousands of families having to double up and triple up in crowded homes and apartments, thus, contributing to another aspect of the homeless problem; and*

WHEREAS, *In the Bush FY 1991 budget proposal, the LIHEAP would be cut another $343 million, or 24 percent, which could eliminate additional hundreds of thousands of households from the program; and*

WHEREAS, *The average residential prices for primary heating fuels are rising and the U.S. Department of Energy projects further increases in 1990; and*

WHEREAS, *States and localities have been unable to adequately deal with normal winter weather needs, and much less cold-weather emergencies and rapid price increases, as evidenced in December 1989; and*

WHEREAS, *Final state decisions have been made regarding most of the oil overcharge funds that the states have received and the amounts committed to LIHEAP are too small to make up for past LIHEAP reductions, much less additional reductions, even if they legally could be used to supplement federal and state resources; now, therefore, be it*

RESOLVED, *That the Executive Committee of the National Association of Regulatory Utility Commissioners (NARUC), assembled at its 1990 Winter meeting in Washington, D.C., reaffirms its support for LIHEAP as a critically needed long term program and urges all Commissions to also actively support both the reauthorization and restoration of funding for LIHEAP; and be it further*

RESOLVED, *That the Executive Committee of the NARUC urges Congress to expeditiously consider and promptly approve the imperative reauthorization of LIHEAP on a long-term basis, and also to appropriate 1991 LIHEAP funds closer to the authorized amount.*

Sponsored by the Committees on Administration and Energy Conservation
Adopted February 28, 1990

Senator **Burdick**. Thank you. Some companies offer discounts for high volume purchases of fuel. Are you aware of any States or companies that provide discounts to the Federal Government for the LIHEAP purchases? If so, how come they encourage this?

Mr. **Rolka**. In Pennsylvania, Senator, I believe there is only one utility company that directly discounts its energy purchases, and that is in the Gas Works in the city of Philadelphia. What we have done in our State is we have attempted to modify the transportation programs for gas services and to come up with some energy assistance programs that we are currently considering, commonly referred to as CAP, variations on percentage of income programs. But we have not come up with a specific program that discounts energy purchases through the use of LIHEAP.

Senator **Burdick**. Thank you.

Mr. **Rolka**. Thank you.

STATEMENT OF DEE EVERITT, CHAIRPERSON, ASSOCIATION FOR RETARDED CITIZENS OF THE UNITED STATES

Senator **Burdick**. Dee Everitt, Association for Retarded Citizens. Please proceed.

Ms. **Everitt**. Senator Burdick, my name is Dee Everitt and I am from Lincoln, NE, and I currently chair the Governmental Affairs Committee for the Association for Retarded Citizens of the United States. I am here to represent—I am also the parent of an adult daughter with mental retardation. I am here to represent our organization, which has 160,000 members, and I am also here on behalf of the 6 million people in the United States with mental retardation.

Mental retardation constitutes almost 15 percent of all the people with disabilities. Levels of mental retardation vary a great deal. Their needs and the needs of the family also vary. Since I am limited on time, I want to concentrate on just a select few programs that we are interested in.

First in the area of special education, we urge your committee to give priority to increasing appropriations to preschool, early intervention, transition, and personnel development programs, as well as the Education for the Handicapped State Grant Program.

For preschool, Congress has promised school systems $1,000 per year reimbursement for next school year. The Congress and the schools are to be congratulated for authorizing and fully implementing this program. We hope Congress will live up to its fiscal promise and fully reimburse the school system, as authorized by Public Law 99-457.

Equally important is the early infant intervention program serving infants and toddlers with handicaps. Many States are deciding now whether they should opt into this program next year. Many of their decisions will be based primarily on the level of commitment by the Federal Government to fund the program. We recommend a funding level of $160 million for part H program to successfully launch the service phase.

An important component of the Education of the Handicapped Act provides funds to operate parent training centers. These centers assist parents to understand their rights and responsibilities under Public Law 94-142. Unfortunately, nine States do not have such centers, primarily due to funding limitations. It is important Congress appropriate sufficient funds to allow for a parent training center in each State for these parents.

The Department of Education statistics indicate a shortage of 5,000 teachers to educate children with mental retardation. These shortages must be addressed immediately, and we recommend the special education personnel preparation program be funded at $94 million to address teacher shortages and the expansion of the parent training center.

Although Public Law 94-142 is incredibly successful, almost 70 percent of the children disabilities are doing practically nothing 1 year after graduating and dropping out, or aging out of school. Approximately 70,000 persons with mental retardation, according to a survey that the ARC of the United States did, are currently on waiting lists for adult services.

The transition program under EHA needs to be expanded. We spend $1.5 billion in Federal dollars in special ed, but only $7 million to assist more than 200,000 special ed students who exit schools to transition into an adult world. We recommend that at least $30 million be appropriated next year for this program.

And finally, two very important programs within the Rehab Act to prepare young adults with mental retardation for work. They are the Vocational Rehabilitation State Grant Program and the Supported Employment State Grant Program. Both of these should be funded at their fully authorized level of $1.8 billion and $31 million, respectively.

PREPARED STATEMENT

Mr. Chairman, Senator Burdick, since the needs of persons with mental retardation are lifelong, there are many other Federal programs that we are obviously very interested in. We need your support and attention, as we have gotten in the past. We thank you and the members of the committee for your strong support, and we hope you will again allow our programs to expand.

Senator **BURDICK**. Thank you.

Ms. **EVERITT**. Thank you.

[The statement follows:]

STATEMENT OF DEE EVERITT

Mr. Chairman, it is a pleasure and an honor to appear before you today on behalf of the Association for Retarded Citizens of the United States (ARC), an organization of 160,000 members throughout the country, most of them parents of children and adults with mental retardation, dedicated to improving the quality of life of all persons with mental retardation. The ARC is greatly appreciative of your outstanding efforts as Chairman of the Subcommittee on Disability Policy to secure rights protections and program expansions for Americans with disabilities.

There are an estimated six million individuals with mental retardation in the United States. Mental retardation thus constitutes almost 15 percent of all persons with disabilities. There are persons with mental retardation of all ages; from infants to senior citizens. Levels of retardation vary widely, from mild retardation to severe and profound retardation. Given the diversity of the severity of the disability and that mental retardation affects persons of all ages, the needs of persons with mental retardation and their families vary greatly.

Parents of persons with mental retardation need help to maximize their child's ability to learn, to work and to live as independently as possible in their communities. Government must and does play an important role in providing education, training, housing and other vital services. There are dozens of federally supported programs which assist persons with mental retardation. Since my time is limited, I would like to spend a couple of minutes concentrating on several very important programs. First, in the area of special education, we urge this subcommittee to give priority to increasing the appropriations to the

Preschool, Early Intervention, Transition and Personnel Development Programs, as well as the Education for the Handicapped State Grant Program.

For the Preschool Program, the Congress has promised school systems a $1000 per child reimbursement in the next school year. We expect all children with disabilities from ages three through five will be receiving special education services next year. This is an outstanding achievement. The Congress and the schools are to be congratulated for authorizing, funding, and fully implementing this critical program. We hope that Congress will live up to its fiscal promise and fully reimburse school systems as authorized by P.L. 99-457.

Equally important is the Early Infant Intervention Program to serve infants and toddlers with handicaps. Most states will decide next year whether or not to opt into this program. Many of those decisions will be based primarily on the level of commitment given by the Federal Government to fund this program. We recommend a funding level of $160 million for the Part H program to successfully launch its service phase.

It is essential that parents meaningfully participate in the development of their child's special education program. Parenting a child with mental retardation can be difficult and so is attempting to understand the several laws and regulations affecting that child's future. An important component of the Education of the Handicapped Act provides funds to operate parent training and information centers. These centers assist parents to understand their rights and responsibilities under P.L. 94-142. After training, many parents have been able to secure a better education for their child. Unfortunately, nine states do not presently have a parent training center, primarily due to funding limitations. It is important that the Congress appropriate sufficient funds in the Special Education Personnel Development Program to allow for a parent training center in each state.

Recent Department of Education statistics also indicate a 5,000 teacher shortage last year to educate children with mental retardation. Other disability groups also have significant teacher shortages as well. We want our children to be educated by qualified teachers. Our children deserve no less. These teacher shortages must be addressed immediately. We recommend the Special Education Personnel Preparation Program be funded at $94 million to address the teacher shortages and the expansion of the parent training centers.

P.L. 94-142, guaranteeing a free, appropriate education for all children with handicaps, has proven to be incredibly successful. Yet, almost 70 percent of children with disabilities are doing practically nothing one year after graduating, dropping out or aging out of school. We are spending large amounts of money to educate these children but we are leaving too many to "fall between the cracks" in their adult years. Nearly all persons with mental retardation want to and can work. Yet, a recent ARC survey indicates almost 70,000 persons with mental retardation are currently on waiting lists for adult services. This is a terrible waste, both in social and economic terms. Several programs need to be expanded to better prepare these individuals for jobs. One is the Transition Program under the Education of the Handicapped Act. We spend $1.5 billion Federal dollars in special education but only $7 million to assist the more than 200,000 special education students who exit schools every year to transition into the adult world. This program needs to expand quickly and we recommend at least $30 million be appropriated next year for this program.

Two very important programs within the Rehabilitation Act also play vital roles in preparing young adults with mental retardation for work. They are the Vocational Rehabilitation State Grant Program and the Supported Employment State Grant Program. Both of these programs should be funded at their fully authorized levels of $1.875 billion and $31 million, respectively. This will allow for several thousand additional individuals with mental retardation to be trained to enter the work force, thus making them tax payers instead of tax users.

Mr. Chairman, since the needs of persons with mental retardation are lifelong, many other Federal programs that I do not have the time to review today also need your attention and support. Very important are funding increases for the Jobs Training Partnership Act, the Maternal and Child Health Block Grant, the Title XX Social Services Block Grant and the programs within the Developmental Disabilities Act. We sincerely hope the Congress sees fit to fund these programs at the recommended amounts. Again, Mr. Chairman, we thank you and members of this Subcommittee for your strong support in the past and we hope you will again allow our programs to expand.

The following list of key disability programs compares the current (FY 1990) year's funding with the ARC's FY 1991 recommendations.

Program	FY 1990 Appropriations (in millions)	FY 1991 ARC Recommendation
P.L. 94-142 State Grants	$1,542.6	$3,493.
Preschool Grants	251.5	355.
Early Intervention State Grants	79.5	160.
Special Education Personnel Development	71.	94.
Transition Grants	8.	30.
Vocational Rehabilitation State Grants	1,528.5	1,875.5
Supported Employment State Grants	27.6	31.
MCH Block Grants	553.6	686.
Title XX Block Grant	2,762.	3,300.
JTPA Block Grant	1,729.7	2,711.5
JTPA Pilots and Demos.	30.5	33.5

STATEMENT OF DONALD R. COHODES, ADMINISTRATOR, FEDERAL PROGRAMS, BLUE CROSS & BLUE SHIELD ASSOCIATION

Senator BURDICK. Donald Cohodes, Blue Cross & Blue Shield Association.

Mr. COHODES. Senator Burdick, my name is Donald Cohodes. I am the administrator of Federal programs for the Blue Cross & Blue Shield Association, and I am here today to speak on behalf of the Blue Cross & Blue Shield Medicare Contractors.

Those contractors handle 90 percent of the part A claims under Medicare and handle 67 percent of the part B claims, which translate into nearly 500 million claims a year, and protecting over 3 billion dollars' worth of savings for the Medicare trust fund.

The administration's proposed budget for fiscal year 1991 is a victim of budget politics. What it does is it underfunds operations and overfunds the contingency. The principal gimmick that is employed in this budget package is what we call the phantom 50 million claims. The administration indicates in their estimates that contractors will receive 50 million more claims than they will process. If you accept their estimate, Medicare claim's volumes will grow only two-tenths of 1 percent next year.

Our historical experience has been in double digits. It is astonishing that this is their estimate, and in fact, their guidance to the regional offices around the country still indicates that they are planning for a 10-percent increase. So, in our judgment, this is something of a budget game.

Without funding though, we are going to have a very serious problem. Beneficiaries will be inundating our offices and perhaps your offices with complaints about why their claims are not being paid. Backlogs will grow, and it will cost an enormous amount of money to reduce them.

The second principal problem that we have has to do with the contingency fund. As proposed by the administration, the contingency fund will be used to pay for already enacted legislation. We do not think enacted legislation is a contingency. The money in there, particularly for physician payment reform, is to pay for a program that is necessary and essential, and we believe that that money ought to be included into operations.

We want to urge the committee to recommend an appropriation level of $1.583 billion, putting the full $173 million contingency fund into operations. This would be identical to the administration's total request, but would put the money into operations rather than leaving it in the contingency category. This would result in a current services budget for fiscal year 1991 and would enable us to handle claims processing and payment safeguards at the volume level that will actually result.

We believe also, though, that you could spend additional money on this program and get significant value. More money would pay a return in payment safeguards, beneficiary services could be advanced by investing more in those services, the efficiency of the program could be improved by investing more money in electronic media claims. Also, we have postage costs that we expect will increase over the year, and we will need funding for that.

PREPARED STATEMENT

Last year, all of our offices, and I suspect your office as well, were inundated with calls from outraged seniors about the financing mechanism for catastrophic. The same could happen if 1 out of every 10 Medicare claims is not paid, or if it is paid in a very late manner. It does not have to be this way. We urge the committee to put the full $173 million contingency into operations, and to recommend an appropriation level of $1.583 billion.

Thank you, Senator.

[The statement follows:]

STATEMENT OF DONALD R. COHODES

Mr. Chairman and members of the subcommittee, I am Donald R. Cohodes, Administrator of Federal Programs for the Blue Cross and Blue Shield Association, the organization representing our 74 member Plans throughout the nation.

Under contracts with the Health Care Financing Administration (HCFA), Blue Cross and Blue Shield Plans provide many essential services for Medicare's beneficiaries and their health providers. Our main job is to ensure that nearly 600 million Medicare claims are paid accurately and on time. We also prevent over $3 billion in Medicare overpayments and abusive billing practices. And we have the front line task of implementing the dozens of legislative and administrative changes made to the Medicare program each year and helping the Medicare community to understand and adjust to these complex changes.

Since Medicare began almost 25 years ago, the federal government has relied on its Medicare contractor network to perform these services efficiently and professionally. The program and its beneficiaries have been well served by this partnership and even today the structure represents one of the lowest overhead costs of any federal program.

BCBSA Position on the FY 1991 Budget

I wish that I could report to you that the Administration's Fiscal Year 1991 budget will be sufficient to ensure that the Medicare program will be properly administered and that claims will be paid on time. Unfortunately, we must again advise you that the Administration's budget is clearly not adequate. Additional funds will be needed to meet Medicare's growing service demands.

The Administration's FY 1991 budget provides $1.4 billion for the Medicare contractor operating budget, only a 4 percent increase over the FY 1990 level. However, for the contingency fund, which is available for expenditure only if released by the Office of Management and Budget (OMB), the Administration has proposed an unprecedented 75 percent funding increase over last year.

The basic problem with the Administration's budget is that it underfunds the operating budget by failing to account for the real growth in Medicare next year and overfunds the contingency account which is intended to cover only unforeseen workload situations. To remedy this imbalance, we recommend that the **$173 million requested for the contingency fund instead be appropriated to the operating budget for a level of $1,583 million.** Our proposal is identical to the Administration's total request, but increases essential operating funds to the level needed to avoid payment backlogs and to prevent improper Medicare spending. The Administration's budget, which proposes to meet these basic program needs by increasing the contingency budget, provides no assurance that Medicare's core responsibilities will be met.

Our recommended budget would meet the growth in beneficiary claims and provide for the implementation of enacted legislative reforms; in other words, it is a true current services budget. Beyond maintaining current services operations, we would support funding for four additional priorities: 1. enhanced efforts to safeguard Medicare from erroneous and improper payments, 2. improved outreach and communications with Medicare's benficiaries, 3. increased emphasis on provider submission of claims electronically and 4. required funding for postal rate increases. These priorities would require approximately $50 million above our recommended $1,583 funding level.

The Consequences of Inadequate Funding

The Medicare contractor budget is a workload-driven program. Its costs are largely determined by only two factors: the estimate of the number of claims that Medicare will receive and the cost per claim of handling this workload for the federal government. If the budget had been based on reasonable estimates for these two factors, I would have little doubt about our ability to handle Medicare's operational demands next year. But that is not the case this year.

The Administration's budget relies on the unfounded and unrealistic assumption that there will be essentially no growth in Medicare claims in FY 1991. By contrast, our estimate assumes that Medicare's beneficiaries and providers will be entitled to payment for over 50 million additional claims next year, workload which has not been funded in the Administration's request. These new claims are due to the continued growth in the Medicare population and in the number of health care services that they receive.

If Medicare's beneficiaries are to receive the payments and services to which they are entitled by law, then Medicare's administrative budget must keep pace with the program's growth. To put it simply, the Administration's budget is only adequate to pay approximately 550 million Medicare claims within time period mandated by Congress. However, once these budgeted funds are spent, Medicare can still expect another 50 million claims for which payment must be made. The failure to account for these additional claims means that Medicare's legislated 24-day payment deadlines cannot be met and claims will pile up in backlogs of unacceptable proportions. The result will not only be that providers and beneficiaries are frustrated by the payment slowdown, but Medicare will be required, by statute, to pay interest penalties on the millions of late payments. If additional funds are not provided to meet the additional claims volume, then legislation to authorize a slowdown in the Medicare prompt payment period will be required.

Implementing Physician Payment Reform

A second major defect with the Administration's budget is that the costs of legislation that has been enacted by Congress — Medicare physician payment reform and other mandated legislative reforms — have not been adequately funded in the operating funds that are immediately available to contractors. Rather, the Administration's budget proposes to fund these new initiatives by increasing the Medicare contingency account.

Vigorous implementation of enacted legislation is not a contingency. Funding will be needed to make sure that congressionally-mandated changes to Medicare are carried out as intended and on time. We strongly advise that Congress not fund enacted legislative reforms by increases in the contingency fund. Rather, these costs should be included in the operating budget.

The Administration's approach would give OMB broad authority to determine the circumstances, the amount and the timing of the release of contingency funds. However, our experience with contingency funds is that circumstances are rarely perceived by OMB to warrant the release of additional funding. We also believe that this approach sends the Medicare community a weak, mixed message about the commitment to carry out legislative reforms and provides Congress no assurance that the promise of physician payment reform and other legislative requirements will be fulfilled.

Payment Safeguard Funding

The Administration's budget proposes no real increase for Medicare payment safeguard activities, the operations by Medicare contractors that prevent Medicare overpayments and abusive billing practices.

Your leadership, Mr. Chairman, in this area has been extremely important and we share your commitment to making sure that Medicare is a prudent payor for health care services. We also share your disappointment that the Administration's budget does not give much greater priority to the auditing and claims review activities that result in over $3 billion in savings each year for the federal budget, the American taxpayers and Medicare's beneficiaries.

Our proposed budget for Medicare contractors provides approximately $25 million above the Administration's request for payment safeguards operations which would restore these vital activities to current services levels. We also believe that investments beyond this level will still provide hard, positive savings by protecting Medicare from improper payments.

Conclusion

The Blue Cross and Blue Shield Association urges that an operating budget of $1,583 million be appropriated for Medicare's claims payment contractors to meet the growth in Medicare claims volume next year, to implement new legislative reforms such as the physician payment initiative and to protect Medicare from billions of dollars in overpayments and abusive billing practices. In addition, we recommend that the subcommittee consider providing approximately $50 million beyond this level for priority enhancements to Medicare's operations. We remain committed to the sound management of the Medicare program. We offer our assistance to you as you determine Medicare's funding needs for the year ahead and we look forward to working closely with the subcommittee on these important issues.

Senator **BURDICK**. In your opinion, is the contingency fund necessary?

Mr. **COHODES**. I believe there is a need for an additional contingency fund. There are always unanticipated events over the course of the year: new legislation, unexpected volume or particular problems for which the contingency can be put to good use.

Senator **BURDICK**. Thank you.

Mr. **COHODES**. Thank you, sir.

STATEMENT OF VINCE DORAN, DIRECTOR, PITTSBURGH JOB CORPS CENTER, HOME BUILDERS INSTITUTE

Senator **BURDICK**. Vince Doran, center director of Pittsburgh Job Corps Center.

Mr. **DORAN**. Good afternoon, Senator, staff. I am pleased to appear before you today to present a statement on behalf of the Job Corps Committee in Community of Business, Labor, and National Volunteer Organizations. My name is Vince Doran and I am currently the center director of the Pittsburgh Job Corps Center.

For over 17 years, I have had the privilege of working with America's youth, and have seen thousands of youth recruited, trained, and placed through the Job Corps Program. Senator, the Job Corps community sincerely appreciates this opportunity to appear before you today and submit facts concerning funding needs for our program in fiscal year 1991.

Nearly 1.5 million of our Nation's at-risk youth have been able to improve their lives and make positive contributions to our society as a direct result of this subcommittee's past support.

There are three issues that we want to briefly discuss with you today. First, the administration's budget request includes some dubious assumptions, some of which are that a savings of $4.6 million will be achieved by establishing undefined, JTPA linkages; that inflation will not exceed 3.8 percent above the 1990 levels; and that 600 Job Corps II slots will be eliminated or kept in place at the expense of eliminating equal number of slots at existing centers. The Job Corps community believes these assumptions are very questionable.

Second, Job Corps will phase a $10.4 million shortfall beginning in July 1991. The administration does not intend to request funds to address this shortfall. Instead, DOL is planning to eliminate 884 training slots or roughly 1,500 students until program year 1991. The Job Corps community stands united in opposing these slot reductions.

Third, with respect to fiscal year 1991, the Job Corps community has established six program priorities.

First, Job Corps must maintain the current slot levels of operations at existing centers and open two of the new centers in program year 1990.

Second, there is a dire need for center repair and relocations throughout this country.

Third, we need to target funding for the current Job Corps II pilot and demonstration projects.

Fourth, there is a major need to develop and implement comprehensive drug and alcohol abuse services. Senator, over 89 percent of our clients have experimented with drugs in the past.

Fifth, the student living and readjustment allowance needs to be increased.

And finally, we would like a specific annual Job Corps budget for program innovations and improvements, including residential child care, computer literacy, and homeless youth programs.

Senator, these are the goals and concerns of the Job Corps community. We come to you today to ask for the resources and commitment to carry on our efforts. Our total funding request for fiscal year 1991 is $898.5 million.

PREPARED STATEMENT

We have seen that Job Corps pays extraordinary dividends for our country and the young people it serves. I speak to you as a representative of the Job Corps community and as someone who cares deeply about the future of our Nation and its youth.

We thank you for your time and the opportunity to present this statement.

[The statement follows:]

STATEMENT OF VINCE DORAN

I am pleased to appear before you today to present this statement on behalf of the Job Corps community of business, labor and national volunteer organizations. My name is Vince Doran. I am currently the Center Director for the Pittsburgh Job Corps Center. As an administrator in the Job Corps program for over 17 years, I have had the privilege of working closely with Job Corps students and have seen thousands of youths recruited, trained and placed through Job Corps.

Mr. Chairman, the Job Corps community sincerely appreciates this opportunity to appear before you today and submit facts concerning funding needs for the program in Fiscal Year 1991. Nearly one and a half million of our nation's at-risk youth have been able to improve their lives and make positive contributions to our society as a direct result of this Subcommittee's support.

There are three issues I want to briefly discuss with you today; specifically, the Administration's FY 1991 Job Corps budget request, the current FY 1990 Job Corps operations budget shortfall, and the Job Corps community's program priorities for FY 1991.

The Administration's budget request recommends a small increase for Job Corps, but it is less than the CBO or OMB projections for inflation. It also includes some dubious assumptions that could potentially weaken the program. They are as follows:

- *DOL plans to increase the percentage of allowable non-residential slots. - DOL estimates it can save $1.6 million by increasing the percentage of allowable non-residential slots above 10%. DOL has not stated whether this increase will occur at the expense of existing residential slots.* **If residential slots are eliminated, this move will strike at the very heart of what has made Job Corps successful - its residential environment.**
- *Savings of $4.6 million are achieved by establishing "JTPA linkages and economies." - The Administration has not specified what linkages would be established, nor how the $4.6 million figure was obtained. DOL officials testified that the $4.6 million in savings was a "best guess estimate."*
- *Inflationary increases do not exceed 3.8% above 1990 levels. - Recent history illustrates that OMB assumptions concerning inflationary increases have been short of actual inflation levels. Because Job Corps operates on a fixed-slot basis, this means the number of personnel, the quantity of supplies and level of support services on a Job Corps center are based on a certain standard of services for a specific number of training slots. As costs for vital center services exceed actual appropriations, centers are forced into deficit spending. When Gramm-Rudman sequestration is factored in, you can begin to see why Job Corps operations budget shortfalls occurred in PY 1988, 1989, and 1990.*
- *Six hundred Job Corps II slots are eliminated or kept in place at the expense of eliminating equal numbers of slots at existing centers. - Job Corps initiated the Job Corps II programs with the intent to increase effectiveness in management, teaching, counseling, and training on*

Job Corps centers. Several years of effort have now gone into these programs, and many are just beginning to come to fruition. It would be a misuse of time, effort, and money to eliminate these programs now. We also do not want to maintain these programs by eliminating slots at existing centers.

In conclusion, Mr. Chairman, the Job Corps community believes that these assumptions are very questionable, and may, in fact, be extremely detrimental to the long-term sustenance of Job Corps.

FY 1990 JOB CORPS OPERATIONS SHORTFALL

Mr. Chairman, besides the Administration's FY '91 budget request, the Job Corps community wishes to make you aware of a disturbing development. Job Corps will face an operations shortfall starting July, 1990. The shortfall is due to the $10.4 million sequestration applied to the Job Corps operations account and the congressional directive to maintain the Job Corps II nonresidential pilot centers. (Job Corps must target funds from the regular center operations budget in order to maintain the pilot centers.) The Administration, however, does not intend to request funds to address this shortfall. Instead, DOL is planning to eliminate 884 training slots, (which is roughly 1500 students), until PY 1991. This reduction will come at a time when Congress has expressly made its intent clear to expand Job Corps and open new centers. **The Job Corps community stands united in opposing these slot reductions.** *A reduction in training slots not only reverses Congressional intent, it means that nearly 1500 young people will be denied the opportunity to participate in Job Corps.*

FY 1990 JOB CORPS FUNDING REQUIREMENTS

With respect to FY 1991, the Job Corps community has established six program priorities. We ask for your help in considering these items and in making these goals a reality:

1. **Job Corps must maintain the current levels of operations at existing centers (40,544 slots), and open two of the new centers in PY 1990 (569 slots).** *Job Corps teacher and staff salaries are still below labor market levels in most areas. Job Corps center liability insurance and staff health care insurance costs have skyrocketed. Contract renewals will exceed Administration projections by $20 million. In order for Job Corps to overcome these obstacles, sufficient funding is needed that reflects a long-term investment in the program.* **FY 1991 Funding Request: $802 million (based on a 4.6% CBO inflation rate and an additional $20 million for contract renewals).**

2. **Address the need for center repairs and relocations.** *A tremendous need exists within Job Corps to address a backlog of centers requiring repairs. The need for repairs or rehabilitations has surpassed allotted funding levels for several years. On too many occasions, funds earmarked for center repairs have been transferred to the Job Corps operations budget. Many Job Corps centers are also located in facilities that were originally intended to be temporary, or that were never intended to be used in education and training efforts.* **The Grafton, Detroit,**

Charleston, Atlanta, *and* **Cincinnati** *centers are among those centers that fall into this category and have been targeted for relocation. Last year, this committee began to address the need to relocate centers.*

FY 1991 Funding request: $37 million for center renovations and repairs; $15.7 million to continue center relocations begun last year.

Provide targeted funding for Job Corps II pilot and demonstration projects while conducting independent evaluations to determine the cost-effectiveness of these programs. *Established in 1986, Job Corps II currently encompasses approximately 600 non-residential training slots in addition to the existing 40,544 Job Corps slots. Job Corps II programs include four urban nonresidential centers, orientation and assessment pilot programs, and nonresidential child care linkages. As I stated earlier, the Administration did not request funds to continue to operate these programs.* **Their survival depends on at least one year of earmarked funding apart from the regular center operations budget.**

FY 1991 Funding Request: $8.6 million for continued operation of Job Corps II programs.

Provide funds to develop and implement comprehensive drug and alcohol abuse services. *Approximately 89% of all Job Corps enrollees, when surveyed, stated they had used alcohol and/or illegal substances. Approximately 60% of these corpsmembers acknowledged using substances within 30 days prior to coming to the centers. Job Corps counselors labor under counselor to student ratios of 90:1 - some even as high as 120:1. If Job Corps is to begin to adequately address the problems of student alcohol and substance abuse, adequate resources for medical treatment, counseling and experienced professional center staff are needed immediately. It is time to confront this crisis - not merely with additional testing, but also by hiring qualified professionals.*

FY 1991 Funding Request: $15 million for alcohol and substance abuse prevention ($11.7 million to hire 369 additional qualified professional staff, $3.3 million for expanded substance intervention and prevention programs).

Increase the student living and readjustment allowances annually. *The living and readjustment allowances are crucial to Job Corps students and are also major factors in attracting and retaining Job Corps enrollees. The living allowance is a monthly allotment to buy needed supplies for everyday living. The readjustment allowance is accumulated throughout a student's stay in Job Corps, and helps graduating students make initial payments for the costs of housing, moving, security deposits, tools for the job, buying autos and auto insurance.* **There have been no increases in the living and readjustment allowances since the inception of JTPA.** *The value of the dollar has eroded by more than 35% since current allowance rates were set. Placement has become tougher year after year because 99% of all employers require transportation.*

FY 1991 Funding Request: $3.5 million (based on indexing allowances at a 4.6% inflation rate starting in PY 1991).

6. **Provide a specified annual Job Corps budget for program innovations and improvements.** *Job Corps is constantly challenged to keep pace with workplace technologies while addressing the many needs of its special students. For example, child care has become an issue that Job Corps must address nationally. Job Corps is mandated to have a 50/50 ratio of males to females. Job Corps has never approached the required enrollment percentage of females. This is due, in large part, to the growing numbers of single mothers that are unable to participate in Job Corps because of the lack of child care services and facilities. 90% of Job Corps is residential and yet, no residential child care services or facilities have been developed on Job Corps centers. Computer literacy is another issue of the 1990's. Employers today expect incoming employees to be trained in basic computer proficiency. Funds are required for staffing and equipment, as well as program development and implementation of a system-wide computer literacy initiative.*

FY 1991 Funding Request: $16 million

Mr. Chairman, these are the goals and concerns of the Job Corps community. We come to you today to ask for the resources and commitment to carry on. Our total funding request for FY 1991 is $898.5 million. We have seen that Job Corps pays extraordinary dividends in the long run for young people in trouble. I speak to you as an administrator, as a representative of the Job Corps community, and as someone who cares deeply about the future of our nation and its youth. I thank you for your time, and the opportunity to present this statement.

Senator **Burdick**. What role does child care have in your program?

Mr. **Doran**. Well, currently there are a few centers that offer nonresidential child care services. I know, thanks to one of your colleagues, Senator Specter, that we are going to open a child care center for our nonresidential students at the Pittsburgh center, beginning in July.

However, there is a tremendous need across the Nation, and in particular for the residential students. Many of the students come from locations that are not adjacent to centers and the only way they will be able to—there is a large population that the only way they would be able to participate in the Job Corps Program is if they could bring their children along. We just do not have that resource right now.

Senator **Burdick**. Thank you very much.

Mr. **Doran**. Thank you, Senator.

SUBCOMMITTEE RECESS

Senator **Burdick**. The subcommittee will stand in recess until 9:15 a.m., Wednesday, March 21. At that time, the subcommittee will continue public witness hearings on the administration's fiscal year 1991 budget request and the hearings will be held in room SD-192. Thank you all.

[Whereupon, at 12 noon, Tuesday, March 20, the subcommittee was recessed, to reconvene at 9:15 a.m., Wednesday, March 21.]

DEPARTMENTS OF LABOR, HEALTH AND HUMAN SERVICES, AND EDUCATION AND RELATED AGENCIES APPROPRIATIONS FOR FISCAL YEAR 1991

WEDNESDAY, MARCH 21, 1990

U.S. SENATE,
SUBCOMMITTEE OF THE COMMITTEE ON APPROPRIATIONS,
Washington, DC.

The subcommittee met at 9:18 a.m., in room SD-192, Dirksen Senate Office Building, Hon. Arlen Specter presiding.

Present: Senators Specter, Bumpers, and McClure.

NONDEPARTMENTAL WITNESSES

Senator SPECTER. Good morning, ladies and gentlemen. The subcommittee will now commence.

This morning we continue with the second of 6 days of public witnesses focusing on programs funded by the Subcommittee on Labor, Health and Human Services, Education, and 20 related agencies. Regretfully, we do not have an adequate amount of time to hear all of the important information which public witnesses seek to present, but to the maximum extent possible we try to accommodate as many people as we can.

Regrettably, the amount of time is limited to 3 minutes per witness. The schedules here are incredibly complicated, as I think you already know. This morning, for example, I am due in the Constitution Subcommittee at 10 a.m., the Foreign Relations Committee at 10 a.m., and we also have a vote at 10 a.m., which gives you some idea as to the variety of demands. We may have to recess the session and come back to it, but we will begin at this time.

I am pleased to call at this moment on a very distinguished Pennsylvanian, Ms. Lee Ducat, who has done outstanding work. She is representing the National Disease Research Interchange.

Ms. Ducat, would you step forward, please.

[No response.]

STATEMENT OF ROBERT B. KNUTSON, CHAIRMAN, EDUCATION MANAGEMENT CORP.

Senator SPECTER. We are going to defer Ms. Ducat for a few moments and go at this point to Mr. Robert Knutson, chairman of the Education Management Corp.

Welcome, Mr. Knutson. You may proceed.

Mr. **Knutson**. Good morning, Senator Specter. I am Robert B. Knutson, chairman and chief executive officer of Education Management Corp., the parent organization of the eight art institutes located around the United States. The art institutes have 12,000 students in associate and bachelor degree programs. Our students come from all 50 States and 45 foreign countries. We are pleased to share with you our observations on the fiscal year 1991 Education Department budget and the difficult budget and program choices you face in meeting the education and training challenges of the 1990's and beyond.

Let me summarize the points I hope you will keep in mind during your deliberations.

First, the student loan default problem did not occur overnight and will not go away overnight. Solving the $1.9 billion loan default maze will take time and patience to determine if the initiatives we have already taken will work. Federal policy both authorizing and budgetary has operated to constrain your ability to address the underlying causes of student loan defaults or the imbalance of loan and grant aid.

Second, we must provide more grant aid to needy low income students. Assuring real access and choice and fulfilling the Nation's commitment to equal opportunity in higher education requires the Congress and the President to replace words with financial resources. We strongly recommend that the Pell grant maximum be increased to $2,500 from the current $2,300 and that the Supplemental Educational Opportunity Grant Program be funded at $500 million in fiscal year 1991.

Third, you must provide the Department of Education with the resources it needs to solve the student loan default problem. It is critical to establish an efficient eligibility and certification process.

Senator **Specter**. Mr. Knutson, how do you suggest that we solve the default problem?

Mr. **Knutson**. The default problem is one that is more complex than it might seem on the surface; the imbalance, for example, between grant and loan funds. Let me give an example, if I might.

Fourteen years ago when the first grant program was established, the grant was $1,400. If you inflate education cost at 8 percent over that period of time, the Pell grant today should be over $4,000. Instead, it is $2,300. So we are making loans to low-income students, and every study that has ever been done showing loans made by banks and attracting those loans back to educational institutions or to guarantee agencies shows a direct correlation in the propensity to default to the income level of the borrower.

Further, we have had massive problems in loan servicing and collection in the banking system, and we have financial aid regulations and programs which are a maze of confusion.

May I continue with my statement, Senator?

Senator **Specter**. By all means.

Mr. **Knutson**. I would be glad to address that question in further detail.

It is also critical to ensure cooperation among the Department of Education, the State regulatory agencies——

Senator **Specter**. Mr. Knutson, take an extra minute or so because I have interrupted you with a question.

Mr. **Knutson**. Yes, sir; I will be able to do that in a minute. Let me repeat the last statement.

It is also critical to ensure cooperation among the Department of Education, the State regulatory agencies and institutional accrediting bodies and to effectively monitor all program participants, especially problem schools. The school accrediting organizations, the Veterans Administration, the respective States, the U.S. Department of Education, the inspector general, and others all have information on schools with problems, and that information is not shared. It is not coordinated. All parties must be directed to work together.

Fourth and last, this committee must be sure that its actions are sector blind and neutral insofar as they impact on the ability of the traditional and proprietary sectors to meet the needs of the students they enroll. Taxpaying institutions have not cornered the market on wrongdoing, and many are more effective at what they do than institutions in the traditional sector.

PREPARED STATEMENT

Equity and fairness require that each school, college, and university be judged on its own merit. We must preserve the right of all students to have access to postsecondary education at the accredited institution of their choice.

My last sentence, sir, is that as a nation I feel that our most important investment is education because it is our future.

[The statement follows:]

STATEMENT OF ROBERT B. KNUTSON

GOOD MORNING, MR. CHAIRMAN AND SENATOR SPECTER. I AM PLEASED TO JOIN YOU AND THE MEMBERS OF THE SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES AND EDUCATION APPROPRIATIONS AS YOU CONSIDER THE FISCAL YEAR 1991 APPROPRIATIONS FOR THE DEPARTMENT OF EDUCATION. AS WE ENTER THE LAST DECADE OF THE 1990s, WE FACE NO MORE CRITICAL CHALLENGE THAN TO EDUCATE AND TRAIN OUR PEOPLE FOR THE EMPLOYMENT OPPORTUNITIES AND PRODUCTIVITY DEMANDS IN OUR FUTURE.

WE AT EDUCATION MANAGEMENT CORPORATION HAVE ONLY A SMALL ROLE TO PLAY IN FULFILLING THAT OPPORTUNITY AND MEETING THAT DEMAND, BUT THOSE OF US IN THE PROPRIETARY OR PRIVATE CAREER SECTOR OF HIGHER EDUCATION HAVE A MAJOR ROLE TO PLAY IF AMERICA IS TO MEET THAT CHALLENGE.

MY COMMENTS TODAY REFLECT THE COLLECTIVE PERSPECTIVES OF THE EIGHT ART INSTITUTES WHICH ARE PART OF EMC, AND ARE LOCATED IN PITTSBURGH AND PHILADELPHIA, PENNSYLVANIA, ATLANTA, GEORGIA, FORT LAUDERDALE, FLORIDA, DALLAS AND HOUSTON, TEXAS, SEATTLE, WASHINGTON, AND THE COLORADO INSTITUTE OF ART IN DENVER. WE ENROLL 12,000 STUDENTS ANNUALLY FROM ALL 50 STATES AND 45 FOREIGN COUNTRIES. SOME 40% OF OUR STUDENTS PREVIOUSLY HAVE ATTENDED OTHER POSTSECONDARY INSTITUTIONS.

WE ARE REGIONALLY AND NATIONALLY ACCREDITED. WE OFFER ASSOCIATE AND BACHELOR DEGREES, AS WELL AS CERTIFICATES THROUGH OUR EVENING CONTINUING EDUCATION PROGRAMS. COLLECTIVELY, THE ART INSTITUTES ARE THE NATION'S SINGLE LARGEST SOURCE OF COMMERCIAL ARTISTS; AND ARE MAJOR TRAINERS OF PHOTOGRAPHERS, INTERIOR DESIGNERS, PERSONNEL FOR THE RETAILING, MUSIC AND VIDEO INDUSTRIES.

THE EIGHT ART INSTITUTES HAVE BEEN IN OPERATION FOR AN AVERAGE OF 32 YEARS EACH, AND MY COMPANY HAS COMMITTED MORE THAN $90 MILLION OF PRIVATE CAPITAL TO FACILITIES AND EQUIPMENT TO EDUCATE OUR STUDENTS. OUR 1,700 FACULTY AND STAFF MEMBERS SHARE IN THE OWNERSHIP OF EMC, AND THEIR INTEREST AND PRODUCTIVITY CONTRIBUTE TO THE SUCCESS OF OUR STUDENTS AND OUR COMPANY.

WE ARE PROFESSIONALS IN THE MANAGEMENT OF STUDENT FINANCIAL AID FUNDS. OUR STUDENT LOAN DEFAULT RATES AVERAGE LESS THAN COMMUNITY COLLEGES NATIONALLY.

WE MAINTAIN CONTACT WITH 30,000 EMPLOYERS. ALMOST 90% OF OUR GRADUATES ARE SUCCESSFUL IN FINDING EMPLOYMENT IN THE FIELDS FOR WHICH THEY WERE TRAINED.

WE GIVE OUR STUDENTS TECHNICAL SKILLS, JOB SKILLS AND LIFE SKILLS - QUALITY, INTENSIVE, SPECIALIZED EDUCATION THAT WORKS.

THE UNITED STATES TODAY HAS A POSTSECONDARY EDUCATION SYSTEM THAT IS THE ENVY OF THE WORLD FOR ITS DIVERSITY. STUDENTS COME TO OUR COUNTRY TO EXPERIENCE WHAT THEY CAN'T FIND AT HOME. THEY ATTEND OUR COLLEGES AND UNIVERSITIES AND OUR PRIVATE PROFESSIONAL SCHOOLS SUCH AS THE ART INSTITUTES.

OVER HALF OF OUR POSTSECONDARY VOCATIONAL EDUCATION IS PROVIDED BY PRIVATELY OWNED SCHOOLS WHICH DELIVER CAREER EDUCATION AT A SMALL COST TO THE TAXPAYER AND ARE AN IMPORTANT NATIONAL RESOURCE. MOST HAVE HIGH COMPLETION AND JOB PLACEMENT RATES - THE BEST IN OUR POSTSECONDARY EDUCATION SYSTEM.

EVERY YEAR HUNDREDS OF THOUSANDS OF STUDENTS GRADUATE FROM PRIVATE CAREER SCHOOLS AND FILL JOBS NEEDED BY OUR SOCIETY.

PROJECTIONS FOR THE WORK FORCE IN THE YEAR 2000 TELL US THAT A BACHELOR'S DEGREE WILL NOT BE REQUIRED FOR A MAJORITY OF JOBS. SOME TRADITIONAL EDUCATIONAL INSTITUTIONS HAVE INDEED DISCOVERED THIS FACT AND HAVE DEVELOPED SPECIFIC JOB TRAINING PROGRAMS DESIGNED TO PREPARE STUDENTS FOR THE WORLD OF WORK. IF THIS COUNTRY IS TO COMPETE EFFECTIVELY IN THE WORLD ECONOMY IN THE YEARS AHEAD, WE MUST TODAY SUPPORT A VARIETY OF POSTSECONDARY EDUCATION OPPORTUNITIES.

IN THE TIME ALLOTTED TO ME TODAY I WANT TO DIRECT THE SUBCOMMITTEE'S ATTENTION TO SEVERAL ISSUES OF IMPORTANCE:

THE LOAN DEFAULT PROBLEM DID NOT OCCUR OVERNIGHT; IT WILL NOT GO AWAY OVERNIGHT.

THE PROBLEM OF STUDENT LOAN DEFAULTS HAS PREOCCUPIED BOTH THE EXECUTIVE BRANCH AND THE CONGRESS FOR THE PAST TWO YEARS. LAST YEAR'S $1.9 BILLION APPROPRIATION FOR DEFAULTED LOANS DROVE HOME THE POINT MOST FORCEFULLY -- HOW MUCH BETTER OFF WOULD LOW INCOME STUDENTS AND THE NATION BE IF $1.9 BILLION WERE BEING ADDED TO THE PELL GRANT PROGRAM?

THE PIECEMEAL SOLUTIONS OFFERED IN MOST OF THE LEGISLATION DEBATED IN CONGRESS OR INCORPORATED IN THE JUNE 5, 1989, FINAL REGULATION ON STUDENT LOAN DEFAULT PREVENTION TREATS THE SYMPTOMS, NOT THE PROBLEMS WHICH CAUSE LOAN DEFAULTS IN THE FIRST PLACE.

STUDENT LOAN DEFAULTS DID NOT EMERGE OVERNIGHT, AND NO MAGIC WAND WAVING OR BLAME PLACING WILL CAUSE THE PROBLEM TO DISAPPEAR OVERNIGHT.

IN THE FIRST YEAR OF FULL FEDERAL FUNDING OF THE BASIC GRANT PROGRAM IN 1975, THE MAXIMUM GRANT PER YEAR WAS $1,400. ASSUMING THAT EDUCATION COSTS HAVE INCREASED BY AN AVERAGE OF 8% PER YEAR OVER THE PAST 14 YEARS, THE PELL GRANT TODAY SHOULD BE MORE THAN $4,000. INSTEAD, IT IS $2,300.

HOW CAN ANYONE EXPECT THAT, WHEN LOANS ARE SUBSTITUTED FOR GRANTS, THERE WILL BE ANY DIFFERENT RESULT THAN AN INCREASE IN LOAN DEFAULTS.

AND I NEED TO MAKE A POINT THAT CONTINUALLY IS MISSED IN COVERAGE OF STUDENT LOAN DEFAULTS IN THE MEDIA AND ON CAPITOL HILL:

> STUDENT LOANS ARE MANDATED BY LAW TO BE AWARDED TO PEOPLE BASED ON NEED. THEY ARE NOT BASED UPON CREDIT WORTHINESS, CO-SIGNERS, COLLATERAL, OR CASH FLOW FROM A KNOWN JOB, AS WITH VIRTUALLY EVERY OTHER LOAN MADE BY LENDING INSTITUTIONS IN OUR SOCIETY.

IS A LOAN DEFAULT A DEFAULT WHEN IT SHOULD HAVE BEEN A GRANT IN THE FIRST PLACE?

IT'S A QUESTION OF ALLOCATION OF NATIONAL RESOURCES. ARE WE GOING TO INVEST IN OUR CITIZENS, OR NOT?

THOSE SCHOOLS SERVICING THE LOW INCOME POPULATION - MANY PROPRIETARY SCHOOLS, URBAN AREA COMMUNITY COLLEGES, AND HISTORICALLY BLACK COLLEGES - SHARE A COMMON SITUATION: THE GREAT MAJORITY OF THEIR STUDENTS PAY BACK THE LOANS THEY RECEIVE, BUT A LARGE MINORITY DON'T.

SIMPLY PUT, FEDERAL POLICY FORCES LOW INCOME EDUCATIONALLY AT-RISK STUDENTS TO BORROW TO PAY FOR POSTSECONDARY EDUCATION.

THESE SAME STUDENTS ONCE RECEIVED GRANTS, AND BORROWED SIGNIFICANTLY LESS OR NOTHING AT ALL WHEN THE GRANT AID WAS MORE AVAILABLE AND COLLEGE COSTS WERE LOWER.

WHILE IT WOULD BE A MISTAKE TO DE-EMPHASIZE THE IMPORTANCE OF A STUDENT'S FAILURE TO REPAY A DEBT, IT IS IMPORTANT TO KEEP IN MIND THAT THROUGHOUT THE HISTORY OF THE GUARANTEED (NOW STAFFORD) STUDENT LOAN PROGRAM, THE NET STUDENT LOAN DEFAULT RATE HAS REMAINED BETWEEN 10% AND 15%. THE UNSPOKEN FACT IS THAT THE DEFAULT RATE IS 10%-15% OF A GREATLY INCREASED OUTSTANDING VOLUME. FEDERAL POLICY AND RISING COLLEGE COSTS CREATED THAT INCREASED VOLUME.

IF CONGRESS IS SERIOUS ABOUT REDUCING LOAN DEFAULTS, IT MUST STOP FORCING LOW INCOME STUDENTS TO BORROW TO PAY FOR COLLEGE, AND CREATE A BETTER BALANCE BETWEEN GRANT AID AND LOAN ASSISTANCE.

WE RECOMMEND THAT THIS SUBCOMMITTEE INCREASE THE PELL GRANT MAXIMUM TO AT LEAST $2,500. IN ADDITION, WE RECOMMEND AN INCREASE IN THE APPROPRIATION FOR THE SUPPLEMENTAL EDUCATIONAL OPPORTUNITY GRANT (SEOG) PROGRAM TO $500 MILLION TO SUPPORT MODEST INCREASES IN INDIVIDUAL AWARDS OR NEW AWARDS TO STUDENTS - THEREBY REDUCING THE LOAN DEPENDENCE OF LOW INCOME STUDENTS. WE ALSO URGE THE MEMBERS OF THIS SUBCOMMITTEE TO RETAIN THE FY 1990 FUNDING LEVEL FOR THE STATE STUDENT INCENTIVE GRANT (SSIG) AND THE PERKINS FEDERAL CAPITAL CONTRIBUTION.

THERE ARE OTHER IMPORTANT FACTORS IN THE STUDENT LOAN DEFAULT PROBLEM:

- GOVERNMENT FINANCIAL AID PROGRAMS AND REGULATIONS THAT ARE A NIGHTMARE OF CONFUSION;
- BANKS WHICH HAVE DONE AN APPALLINGLY BAD JOB OF LOAN SERVICING AND COLLECTION;
- AND A FAILURE TO MONITOR SCHOOLS AND LENDERS IN A COORDINATED WAY.

THE SCHOOL ACCREDITING ORGANIZATIONS, THE VETERANS' ADMINISTRATION, THE RESPECTIVE STATES, THE U. S. DEPARTMENT OF EDUCATION, THE INSPECTOR GENERAL AND OTHERS ALL HAVE INFORMATION

ON THOSE WHO ENGAGE IN QUESTIONABLE OR FRAUDULENT PRACTICES - AND INFORMATION ISN'T SHARED, IT ISN'T COORDINATED.

THAT CAN BE FIXED IF ALL THE PARTIES ARE DIRECTED TO WORK TOGETHER. IT MUST BE DONE.

THE DEPARTMENT OF EDUCATION NEEDS THE FULL SUPPORT OF THIS COMMITTEE IN ORDER TO CARRY OUT ITS CRITICAL OVERSIGHT RESPONSIBILITIES. HOWEVER, THIS SUPPORT NEEDS TO COME NOT ONLY IN THE FORM OF ADDITIONAL FUNDING FOR THE INSPECTOR GENERAL, BUT ALSO IN THE FORM OF TRAINING AND MANAGEMENT SERVICES TO PARTICIPATING INSTITUTIONS. THE LAST TEN YEARS HAVE SEEN A 30% REDUCTION IN DEPARTMENT PERSONNEL, WHICH MUST BE RESTORED IN ORDER FOR THE DEPARTMENT TO TIGHTEN UP THE IMPORTANT INSTITUTIONAL ELIGIBILITY PROCESS, AND FOR THE DEPARTMENT TO IMPROVE ITS ABILITY TO WORK WITH THE NATIONAL ACCREDITING AGENCIES AND WITH THE STATE REGULATORY BODIES.

IF THE DEPARTMENT HAD MADE THE NATIONAL STUDENT LOAN DATA SYSTEM OPERATIONAL AFTER THE 1986 HIGHER EDUCATION AMENDMENTS WERE ENACTED, AND CONDUCTED PROGRAM REVIEWS - SOME REAL DATA ON THE SOURCE OF THE PROBLEM FROM AN INSTITUTIONAL DOLLAR VOLUME PERSPECTIVE WOULD BE AVAILABLE - WE MIGHT BE WELL ON OUR WAY TO REDUCING LOAN DEFAULTS. INSTEAD, WE ARE ANXIOUSLY AWAITING THE RESULTS OF OUR INITIAL EFFORTS.

PROVIDING ADEQUATE RESOURCES TO PROPERLY TRAIN CAMPUS STUDENT AID OFFICIALS IN ALL OF THE TECHNICALITIES, NUANCES AND DETAILS OF THE NUMEROUS CHANGES IN THE LAW; THE REGULATIONS AND DEPARTMENTAL POLICIES AND PROCEDURES, AS WELL AS FOR THE EFFECTIVE AND ESSENTIAL MONITORING OF ALL TITLE IV ELIGIBLE INSTITUTIONS, IS CRITICAL. PREVENTING ABUSE AND ERROR AND AVOIDING DEFAULTS, IS VITAL TO THE SUCCESS OF THESE PROGRAMS.

IN THE TRIAD OF INSTITUTIONAL OVERSIGHT BODIES, THE STATES TRADITIONALLY HAVE FULFILLED THE CRITICAL ROLE OF PROVIDING FOR CONSUMER PROTECTION. WE BELIEVE THIS FUNCTION APPROPRIATELY BELONGS TO THE STATES, BUT THE DEPARTMENT OF EDUCATION MUST STRENGTHEN THE MINIMUM STANDARDS FOR STATES IF THE STATE LICENSE IS TO REMAIN A BASIS FOR INSTITUTIONAL ELIGIBILITY FOR PARTICIPATION IN TITLE IV PROGRAMS.

WE FIRMLY BELIEVE THAT THE TRADITIONAL ROLES OF THE DEPARTMENT OF EDUCATION, THE STATES AND THE ACCREDITING ORGANIZATIONS MUST

BE MADE TO WORK AGAIN IN ORDER TO REDUCE OR ELIMINATE THE OPPORTUNITIES FOR ABUSE. CREATING SEPARATE PROGRAMS FOR 'VOCATIONAL' STUDENTS IS INAPPROPRIATE, NOT ONLY BECAUSE A LARGE MAJORITY OF POSTSECONDARY EDUCATION NOW IS EMPLOYMENT ORIENTED, BUT ALSO BECAUSE WE WOULD THEN NEED TWO SETS OF BUREAUCRACY TO MANAGE POSTSECONDARY TRAINING. LET US INSTEAD TRY TO MAKE THE CURRENT OVERSIGHT SYSTEM WORK.

YOU WANT, AND WE WANT, ACCOUNTABILITY IN HIGHER EDUCATION. WE THINK CONSUMERS OF EDUCATION SERVICES AT ALL KINDS OF SCHOOLS SHOULD KNOW WHAT THEIR CHANCES ARE OF COMPLETING A PROGRAM OF STUDY; AND WHEN THEY DO, WHAT THE ODDS ARE OF GETTING A JOB IN THEIR FIELD OF ENDEAVOR.

DEFAULT INITIATIVE HAS BEEN IN EFFECT FOR LESS THAN A YEAR. THERE WERE MAJOR CHANGES IN THE SLS PROGRAM JUST THREE MONTHS AGO. MANY SCHOOLS AND LENDERS HAVE JUST STARTED THEIR DEFAULT REDUCTION EFFORTS. THERE HAVE BEEN A HUGE NUMBER OF CHANGES IN THE LAW IN RECENT YEARS, MANY NOT YET TRANSLATED INTO REGULATIONS.

IT IS NOW TIME TO SHARE SOLUTIONS. WE THEREFORE SUPPORT THE CREATION OF A NATIONAL DEFAULT REDUCTION TASK FORCE, MADE UP OF ALL OF THE VARIOUS PARTIES INVOLVED IN DEFAULT REDUCTION, INCLUDING SCHOOLS, LENDERS, GUARANTEE AGENCIES AND THE DEPARTMENT OF EDUCATION. WE ASK THIS COMMITTEE TO PROVIDE THE DIRECTION TO CREATE SUCH AN INITIATIVE, UNDER THE RESPONSIBILITY OF THE DEPARTMENT OF EDUCATION. ONLY BY JOINING FORCES CAN AN ENVIRONMENT BE CREATED WHICH WILL SUPPORT CREATIVE SOLUTIONS.

IN CONCLUSION: WHAT WE ALL WANT IS TO PRESERVE THE DIVERSITY OF OUR POSTSECONDARY EDUCATION SYSTEM. THIS IS ITS STRENGTH. FREEDOM OF CHOICE AND EQUAL ACCESS ARE ITS FOUNDATION.

AS A NATION, OUR MOST IMPORTANT INVESTMENT IS EDUCATION, BECAUSE IT IS OUR FUTURE.

Senator SPECTER. Thank you very much, Mr. Knutson. You have a lot of supporters on this subcommittee and in the Congress emphasizing the need for education. The administration budget has some increase, and my sense is that we will be adding to it in this subcommittee and that that will be upheld by the Congress.

We thank you very much for your testimony. Your full statement will be made a part of the record and will be studied.

Mr. KNUTSON. May I add in addition to the full statement an article from the Chronicle of Higher Education of March 7, 1990, related to the subject of my testimony?

Senator SPECTER. We would be glad to include that in the record as well.

[The information follows:]

[From the Chronicle of Higher Education, Mar. 7, 1990]

CONGRESS SHOULD REJECT SEPARATE BUT EQUAL AID PROGRAMS

(By Stephen J. Blair)

For millions of our young people, the reauthorization of the Higher Education Act in 1991 may well determine whether or not they have the chance to pursue their vision of the American Dream. For many, the dream centers on a traditional college education, and rightly so. But four-year colleges and universities are hardly the only paths to getting ahead in our society: In fact, only half of our nation's young people go on to traditional colleges.

Fortunately for the other half, the non-college-bound, Congress recognized that traditional higher education isn't—and shouldn't be—the sole option in postsecondary education when it designed federal student-aid programs three decades ago. By making student-aid loans, Pell Grants, and campus-based aid programs available to students regardless of which option they chose—traditional colleges or trade and technical schools—our nation has nurtured a pluralistic system of postsecondary education, one that recognizes that skilled artisans, tradesmen, and technicians are valued members of American society.

Today, though, this pluralistic system is under attack from some leaders in traditional higher education, who have proposed that Congress establish separate financial-aid programs for students attending postsecondary trade and technical schools. Everyone who cares about educational opportunity for all Americans should be alarmed at the very notion of "separate but equal" student-aid programs. For if history teaches us anything about education, it is that separate is inherently unequal.

Intentionally or not, the advocates of separate programs are sending the unmistakable message to non-college-bound young people that their lives and potential contributions to society are not as important as those of college-bound youth. That message debases every non-college-educated American.

Leaving aside for a moment the issue of discrimination—this time on the basis of economic circumstances and career choice—such proposals constitute shortsighted public policy from even the narrowest economic standpoint. For example, the argument that creating a separate financial-aid program for trade and technical schools in the Department of Labor would be cost-effective simply doesn't hold water.

Under the current financial-aid system, the cost per student for taxpayers averages $2,500 for students in private trade and technical schools. By comparison, the Labor Department's programs that train people for jobs cost twice as much per student. Each graduate from a program financed by the Job Training Partnership Act costs taxpayers $5,000. And the Job Corps is significantly more expensive at $15,000 per graduate.

Advocates of separate student-aid programs also overlook the fact that a substantial number of students migrate from one sector of postsecondary education to another. Under their proposal, an individual attending a private trade school could take out a "vocational" student loan and later transfer to a community college and take out an "educational" loan. In all probability, separate student-aid programs would actually encourage excessive borrowing and could be a costly nightmare to administer.

In part, such proposals are a reaction to Congress's growing concern about student-loan defaults and fears that the expense of paying off defaulted loans may reduce the money available for other student assistance at a time when all postsecondary institutions are, to be blunt, in stiff competition for students. Rather than working with trade and technical schools to formulate reforms to address the loan-default problem thoughtfully and pragmatically, some leaders in traditional higher education are intent on serving up our sector to Congress as the scapegoat, as if removing our students from the student-loan program would magically solve the default problem.

Well, it won't. The fact is, of course, that student-loan defaults are a problem for everyone in postsecondary education. All available research demonstrates that the default rate of a postsecondary institution, lender, or guarantee agency is primarily a function of the population served. In addition, the costs of educating at-risk students, and making and administering loans for them, are greater regardless of the type of postsecondary institution that a high-risk student attends.

In this context, it is not surprising that student-loan default rates are higher among students attending trade and technical schools. Compared with traditional higher-education students, those at trade and technical schools are significantly more likely to be high-risk—that is, poor, female, from a minority group, independent of parents' income. They are likely to have scored lower on academic-ability tests.

Several other important factors about trade and technical students too often are overlooked in the debate about student-aid programs:

Sixty-one per cent graduate from their programs, compared with 43 per cent in public community colleges, 58 per cent in four-year colleges, and 33 per cent in the Job Corps.

Eighty-one per cent of the graduates immediately find jobs in their chosen careers.

The graduates make up about half of the skillled entry-level workers in the United States.

But this is not to suggest that leaders of trade and technical schools believe the loan-default problem should be swept under the rug. Far from it. The National Association of Trade and Technical Schools is working closely with the Department of Education and Congress to meet the default problem head on. In 1986, it and several other associations of trade and technical schools launched a comprehensive Default Management Initiative designed to help both schools and students avoid defaults. This initiative has produced results: The Department of Education announced in 1989 that trade schools had posted the largest decrease in loan defaults of any educational sector. And NATTS also has recommended a number of tough legislative proposals to address the default problem, including tightening requirements that institutions refund students' tuition if they drop out and barring loans to students at schools that have withdrawn from an accrediting agency or whose accreditation has been revoked.

It is essential to recognize, however, that a major factor in the increase in student-loan defaults in recent years is the imbalance between grants and loans. Federal policy over the last 10 years has forced our neediest students to rely upon loans to finance their postsecondary education. In 1980, grants constituted 40 per cent of the typical aid package, with loans making up most of the remainder. Now, grants make up only 29 per cent of the typical package.

With the Department of Defense proposing up to $180-billion in cuts in its budget over the next three years, now is the time for all members of the education community to stand together and demand the redress of the brutal imbalance between loans and grants in federal student assistance. We must work together to insure that every student has access to the funds necessary to attend the institution and program of his or her choice.

The fundamental question that we face, as a society, is nothing less than whether our young people will continue to have equal access to, and freedom of choice in, postsecondary education. Because, make no mistake, the separate financial-aid programs advocated by some in traditional higher education will be separate and unequal. Indeed, their proposals will severely restrict a major avenue that at-risk students have used to break out of their current circumstances—and we will be creating two societies divided along the lines of education, the haves and the have-nots.

At a time when the walls of apartheid are inexorably crumbling in South Africa, it would be tragic if here in America we began to build walls of educational apartheid.

Senator Specter. We now have the pleasure of hearing from one of our colleagues, the distinguished Senator from Utah, Senator Garn, who is here with his daughter, Sue Horn.

We also have Mrs. Nancy Thurmond on our agenda. Has Mrs. Thurmond arrived yet?

STATEMENT OF LEE DUCAT ON BEHALF OF THE NATIONAL DISEASE RESEARCH INTERCHANGE AND THE HUMAN BIOLOGICAL DATA INTERCHANGE

Senator **Specter**. We also have Ms. Lee Ducat. Would you like to proceed now?

I understand, Senator Garn, notwithstanding the customary Senatorial privilege, that there has been a request for a deviation here to hear first from your daughter, Sue Horn.

We welcome you here.

Senator **Garn**. If it would be all right, may we hear from Lee first and then Sue, and then I will finish.

Senator **Specter**. We will be glad to proceed in that sequence.

Ms. **Ducat**. It is a great honor to be here with you today, Senator Specter, and to be seated with Senator Jake Garn from the great State of Utah and his lovely daughter, Susan. Senator Garn and I are colleagues in a way that you are not colleagues. We are parents of diabetic children. You know better than anyone else that the Juvenile Diabetes Foundation was started 20 years ago in Philadelphia, and it has grown into a formidable organization with chapters all over the world raising funds for research in the hope that we would cure our children.

I come to you with a monumental problem. We have seen 5 years where the funding for diabetes research has gone like this [indicating].

Senator **Specter**. May the record show that is up with a gesture.

Ms. **Ducat**. No, no; it is down. It is this, like down.

Senator **Specter**. I would suggest you hold the hand the other way, then.

Ms. **Ducat**. It has gone down steadily. I am not experienced in showing graphically how it has gone down, but the fact is that in 1990 the appropriations for diabetes research are $5 million less and more than they were in 1987. The diabetes effort has been devastated. Researchers have been going out of business. The diabetes centers have been cut 25 percent. Research grants have been cut 12 percent. We have had a devastating effect on the way diabetes research has been growing.

I plead with you to support this new initiative which is supported by the scientists, by the National Institutes of Health and NIDDK, which is the Diabetes Institute, and which is supported by a major portion of the diabetes constituency.

We need to search for the diabetes genes. The genes have been found in cystic fibrosis. They have been found in Huntington's disease, and in order to proceed with research we need to find the genes to unlock the doors to diabetes and the susceptibility genes for all the complications of diabetes.

The people affected in our country make a huge constituency. We have some 12 million diabetics, and if you include their parents and their brothers and sisters, the people who care and love them, the research community and the doctors and nurses who treat them every day, you have a huge constituency. In Pennsylvania, as you know, the incidence of diabetes is very great.

I started the National Disease Research Interchange 10 years ago, and since then I have started the Human Biological Data Interchange. Those organizations are helping to support research. I sat at a meeting of researchers just last week at NIH. I sat with the top geneticists, immunologists, and clinicians in the country, and they underscored unanimously the need to find the diabetes genes. They started the race for science to look into the search for the diabetes genes.

Our minorities in our country are affected dreadfully by this disease. Our black people are devastated by it, particularly black women; the Hispanic community, the Chinese community, all of our minorities, and the American Indians. In fact, I heard only yesterday that three American Indian tribes had declared war on diabetes.

So I ask you to consider a funding to the National Institutes of Health of $9 billion. I ask you to support the official request of the director of the Diabetes Institute, Philip Gordon, for $808 million to the Diabetes Institute. I ask you to move courageously as you have always done with the Pennsylvania constituency supporting the diabetes effort from the beginning to fund $50 million into the search for the diabetes genes.

I want to share with you that tomorrow night I am going to be in New York at the Waldorf Astoria where the International Juvenile Diabetes Foundation will be giving me an award for starting the Juvenile Diabetes Foundation and for devoting 20 years of my life to the diabetes effort. I will accept the award, but I will accept it with a really heavy heart because I know better than anyone else that we do not know the cause for diabetes, nor have we found the cure after 20 years.

PREPARED STATEMENT

I urge you to do whatever you can to save our young people, to save this vast group of people in our country who deteriorate every day from diabetes.

Senator SPECTER. Thank you very much, Lee, for your very impressive testimony. Of course, I know of your outstanding work over the years, and we will give your request very, very careful consideration.

[The statement follows:]

STATEMENT OF LEE DUCAT

Mr. Chairman and Members of the Subcommittee:

I am Lee Ducat, and I return to you today as a concerned parent and grandparent, concerned for my son and his children and the 12 million Americans who are afflicted with the dreaded disease known as Diabetes. And I am honored to be before you today with a distinguished panel of parents with diabetic children: Mrs. Nancy Thurmond, wife of the Senate's most senior Member, the Honorable Strom Thurmond, the distinguished senior Senator from Utah, the Honorable Jake Garn and his daughter Susan.

When my son was diagnosed a Diabetic as a nine year old, I was motivated into action, determined to find the cause and the cure for Diabetes by focusing national attention on this debilitating disease that does irreversable damage to our kidneys, our heart, our eyes and our nervous system -- virtually every one of the body's organs -- and disproportionately so to Minority populations like Blacks, Hispanics, Native Americans and Native Hawaiians.

Mr. Chairman, as we begin the last decade of the 20th Century, my mission is not yet complete. The cause of Diabetes is still unknown - it continues to elude or Nation's top researchers. But we are moving closer to a cure. We have the technology.

And 1990 will not doubt be a pivotal year in the history of Diabetes research. This year marks the 20th Anniversary of my founding the Juvenile Diabetes Foundation (JDF). Having since expanded into an international organization, with a membership of over 500,000 families, JDF is the largest volunteer health organization committed to support research to find the cause and the cure for Diabetes and its complications. This year also marks the 10th Anniversary of my founding the National Diabetes Research Interchange (NDRI), which became the National Disease Research Interchange in 1986 when it expanded to serve over 80 disease categories, including Cystic Fibrosis, Cancer, Diabetes Mellitus and Hyaline Membrane Disease.

Most recently I founded the Human Biological Data Interchange (HBDI) with the assistance of JDF. Responding to the scientific research community's discovery that Diabetes is a genetic disease, HBDI's goal is to provide researchers with information and statistics about families with Diabetes to trace the disease throughout the various segments of our population. I am proud to announce that HBDI has produced 135 family cell lines -- a small yet vital first step towards helping researchers pinpoint the Diabetes genes. The scientific research community believes that finding the Diabetes genes will unlock the door to the causes and the cure for Diabetes.

Recognizing that Diabetes genes research should be the Federal Government's major thrust to solve the mysteries of this horrible disease, the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), under the direction of its Director, Dr. Philip Gorden, convened less than one week ago the most eminent researchers from around the country for a meeting he titled "The Search for the Diabetes Genes". As an invited guest and participant at this meeting, I was excited to observe this expert panel reach a consensus on the need to exploit fully the new research leads in this field, and to take advantage of the broad array of new molecular biology techniques, to discover the Diabetes genes. These experts recommend, and NDRI and HBDI support the recommendation, that an additional $50 million above and beyond the $8.5 million NIDDK currently has invested Diabetes genes research, be appropriated to combat the disease that costs our Nation an estimated $20 billion annually. Spending $2.50 to save $1000, to improve the quality of life for some 12 million Americans afflicted with the disease and their families, and the possibility of preventing Diabetes for our future generations, is no doubt a "blue chip" investment of our taxpayers' money!

Doubters may question the worthiness of such an investment in the future health of our Nation. In this respect, I must simply say the investment can and will pay off! Successful NIH-sponsored gene research must not go unnoticed. Quite recently, a massive 5-year effort, spearheaded by NIH, produced the identification, cloning and sequencing of the Cystic Fibrosis gene! This awesome achievement will serve as the catalyst to discover the cause and the cure for Cystic Fibrosis.

And Diabetes, while certainly a more complex disease, in that researchers recognize more than one gene is responsible for the disease, initial breakthroughs have been made which must now be capitalized on by intensifying the Search for the Diabetes Genes. For instance, a dramatic discovery in the last two years has uncovered a Diabetes susceptibility gene in insulin-dependent or Type I Diabetes. This gene appears to be necessary but not completely sufficient to cause the disease. In animal models there is a suggestion that additional genes are involved, but as yet, no other gene has been identified in humans. There is an urgent need to search for these other potential Diabetes genes in insulin-dependent Diabetes.

As promising as these research results are, they cannot be expanded upon or learned from without additional federal funding. The harsh reality is that since NIDDK's Fiscal Year 1987 budget of $510,880,000, its budget has decreased annually in constant, inflation-adjusted 1987 dollars, and it is projected to decrease again under President Bush's Fiscal Year 1991 request to a dismal $490,201,000. During this same timeframe, the budget for the Division of Diabetes also has decreased woefully in constant, inflation - adjusted 1987 dollars to the extent that the President's Fiscal Year 1991 request is a horrific $260,093,000. This represents more than $5,500,000 decline from the Division's $265,723,000 Fiscal Year 1987 budget. Pure and simple: our children -- our Nation's future -- cannot afford to accept this downward spiral. We can and must do better.

NDRI and HBDI strongly support Dr. Gorden's professional judgment request of $808,000,000. This figure takes into account the additional $50 million the Institute needs to support its

Search for the Diabetes Genes initiative. And with respect to NIH, as a whole, we urge funding of $9.237 billion in Fiscal Year 1991.

Since 1970, when I became actively involved with Diabetes, the greatest advances in Diabetes research have been made when the Federal Government, private industry, the scientific research community and the voluntary health organizations have coalesced to put forward a truly concerted effort. Next month, in fact, all facets of this exciting initiative will be represented here in Washington at the "Search for the Diabetes Genes" Capitol Hill Conference, the purpose of which is to determine how we can all work together to promote the discovery of the Diabetes genes. Now is the time to transform our knowledge and quickly evolving genetic technology, techniques and therapy into action to guarantee that the 1990s produce the Diabetes genes!

On behalf of NDRI and HBDI, thank you for this opportunity to present our views. I would be pleased to answer any questions you may have.

STATEMENT OF SUE HORN

Senator SPECTER. I would like to turn now to Ms. Sue Horn. Welcome, and we look forward to your testimony.

Ms. HORN. Thank you. I would like to thank you for the opportunity to testify today. I am going to read my statement. Although my father donated one of his kidneys to me, none of his speaking ability came along with that.

As many people know from my well-publicized kidney transplant, I am a diabetic. At the age of 10 years old I came down with a flu-like viral infection, and soon after that I contracted a very upsetting, treatable, incurable disease called diabetes, although at the time my parents were much more upset than I was because they were able to understand its implications so much better.

I was diagnosed as a type I juvenile diabetic, which meant that my pancreas was not producing enough insulin to keep dangerous levels of sugar from building up in my bloodstream. At such a young age I did not fully understand what that diagnosis meant; however, I was told it had serious implications. Of course, at that age the prescribed daily shot of insulin was something that I at least understood enough to not welcome. At the age of 10, however, it was impossible to comprehend the seriousness of the possible complications that may occur 20 years down the road.

My first day back at school after my hospitalization diagnosis gave me a message of how my disease would be accepted by my classmates and how it might affect the rest of my life, especially my growing up years.

One of the girls in my class had been avoiding me. She came up to me and said, "I do not think I can play with you anymore. I am afraid I might catch what you have." I explained to her that it was not contagious, but this message from one of my friends taught me that from that time forward I would have difficulty fitting in with the other kids, kids that I had always blended in easily with before becoming a diabetic. It boldly sent me the message that being labeled diabetic would label me different for the rest of my life, and that experience was only the beginning of a lifetime of experiences in which my diabetes would continue to separate me from the norm. I would not only be treated differently by other kids, but I realized that to keep the disease under control I would have to treat myself differently.

First of all, I could not neglect my daily insulin shot. I could not have soft drinks with the rest of the kids and eat the kinds of junk food that kids love to eat. I would have to monitor my diet closely and make certain I ate on a regimented schedule, receiving all the proper nutrients and being extra cautious to not eat the wrong kinds of food.

While I knew these changes in lifestyle would be an inconvenience, I had no idea at the time how the disease would invade every single part of my life. Now 20 years later, I feel like an expert on the life of a diabetic. I have continued to take the insulin shots; however, memories of my rebellious teenage years are very vivid when I grew tired of the stifling routines I was forced to adopt. I tried to be like my friends, eating what they ate, trying to live as carefree as they seemed to be living. I wanted to be someone without a health problem, someone who was not treated differently.

I learned quickly, however, that diabetes is not a very forgiving disease and that refusing to accept it does nothing but make it worse. I learned the dangers and frights of hyperglycemia and insulin reaction.

While I must credit insulin for keeping me alive and for helping to keep my sugar levels regulated, I must stress that regardless of its positive contribution to treatment of the disease, insulin is not a cure for diabetes. There is no cure. Insulin helps diabetics cope with the disease, but it does not make the disease go away. It may be a miraculous treatment, but it is certainly not a miraculous cure. It extends life. That cannot be underestimated. At the same time, we cannot use it as an excuse for not vigorously furthering diabetes research. A cure must be found.

Almost daily we hear news about AIDS fatalities and AIDS research efforts, and muscular dystrophy, cancer, and heart disease are well-known diseases that continue to plague us. We know that these are terrible diseases, and we do not scoff at their seriousness. Yet, few realize that diabetes and its complications are a leading cause of death in the United States. It affects 12 million Americans at an estimated cost of over $20 billion.

These statistics may be startling but not nearly as revealing as the actual effects of the disease. An overwhelming number of diabetics suffer from kidney, eye, and heart disease and nerve damage. As a diabetic, I suffered from kidney failure, which presented me with two options: kidney dialysis or an organ transplant. Fortunately, I have living related donors and a generous, loving father who could offer me one of his kidneys.

Even though the transplant gave me a new lease on life, renewed energy and hope, I still have no guarantees from day to day that I will not again have to face kidney failure. I also suffered from the loss of vision in my right eye which will in its deteriorating stages required many laser treatments and, finally, two very complicated surgical procedures which tried but failed to help my failing vision. I have endured two miscarriages which were directly related to the diabetes.

I am eternally grateful for my healthy 5-year old daughter.

I realize how blessed I am to have her. She came 7 weeks early, however, because of my diabetic kidney problems.

These are some of the complications of diabetes. As they demonstrate, diabetes affects every part of a diabetic's health and life. I still check my sugar level at least four times a day, and my life is a constant balancing of health considerations.

I did not outline these to draw sympathy for my situation. I am very fortunate; in fact, more fortunate than most. I outline them to indicate that diabetes is a devastating disease which robs its victims in nearly every area of their lives. It is a disease that needs further research, a disease that needs a cure. If a cure can be found, we must advance toward it. While we naturally react to the complications, we need to aggressively pursue a cure for the root of the complications, the disease itself.

I appreciate the many groups in the country like the National Institute of Diabetes and Digestive and Kidney Diseases and the Human Biological Data Interchange and others who are committed to discovering a cure. I applaud their amazing discoveries and encourage them to press on, especially with their research into the possible diabetes gene.

I hope Congress will see fit to support these research efforts as generously as possible. Thank you very much.

Senator **Specter**. We very much appreciate your testimony. Even more so because of the obvious impact on you when you talk of your 5-year-old daughter. I can understand precisely what you are saying. I have listened to your father in a variety of contexts including a prayer breakfast talk about you, his grandchildren, and your family and the impact of your statement and your emotional involvement is both understandable and lends emphasis to what you have said to us, so we appreciate your sharing those thoughts with us. And I think you are going to be a tough act for your father to follow. Senator Garn?

STATEMENT OF HON. JAKE GARN, U.S. SENATOR FROM UTAH

Senator **Garn**. Well, thank you, Mr. Chairman, and may I say I appreciate the courtesy of being here. In 15 years in the Senate and as a member of the Appropriations Committee for 12, I must admit this is my first testimony as a public witness, and I do appreciate the opportunity of being here. And you are right, Sue is a tough act to follow.

I appear today not as one of your colleagues or as Senator, but as a father of a diabetic. My wife and I were typical of most young parents at the time when we found out that Sue had diabetes. Initially, I was not particularly concerned. When I say initially, for a few hours. Because I think I was like most parents and most people, I did not understand what the disease was all about. And I assumed, like many people do today, that insulin was a cure. As long as you have insulin that there is no problem.

I distinctly remember learning the realities in the first few days in the hospital more than 20 years ago, and having the doctor tell me, do not worry about it, Mr. Garn, he said, as young as your daughter is, there is no doubt in my mind that within 5 to 10 years we will have a cure and you will not have to worry about the complications of that disease.

Well, it is not 5 to 10 years, it is 20 years, and very little is different. Treatment, certainly, is not different. I can remember the first day that we were home from the hospital and Sue and her mother had been practicing how to give shots on oranges. I knew nothing about them.

But time wore on and I had been impressed that first morning that it was important that that insulin shot be given in a very narrow timeframe and they were both sitting at the dining room table crying about the shot. And I said, well give me the syringe, I'll give her the shot. And they said, well, you've had no practice. I said, that's right, I have never given one in my life, but somebody has to do it.

So I gave Sue her first shot, and apparently I was lucky. I gave them less painlessly than her mother, so for a number of years, Sue and I became very close because I was the one that gave her her shot every morning for at least 5 or 6 years, even when she was a teenager. Not that she wasn't capable of giving them to herself, I guess she liked to have daddy give her the shot.

And so all those years we had hope that some type of cure, at least better treatment would come along. But, as has been testified, not much is very different. The only real difference is now we have glucometers rather than testing urine, which is much more accurate and has made it easier for Sue to be able to manage her diabetes.

I was also told by her pediatrician at that time that her mother and I would become experts on our diabetic. That we would learn more about her than he or any other doctor could, and that is true. Sue probably still disputes it, but I can look in her eyes today or listen to the tone of her voice over the telephone, and I can pretty much tell where her sugar level is. She probably still doesn't believe that. She certainly didn't when she was a teenager.

But during those years, I can remember sometimes the denial and having to literally sit on top of her with my knees on her shoulders holding her down while I pried her mouth open to squirt glucose around her teeth and onto her tongue to get her out of insulin reactions.

So it does affect families. It affects entire families. It affected her brothers and sisters, the way we ate and the way her mother cooked. And then as my colleagues know, in the middle of all of this when she was 17, she lost her mother. So it does affect entire families. And again Sue and I are not here for your sympathy.

I am a member of the Appropriations Committee. I know how difficult 302(b) allocations are. I know how I'll be fighting for NASA funding and space shuttle funding, and so I am well aware of the difficulties and all the requests from public witnesses for other problems that come under the jurisdiction of this subcommittee.

So I am not here to request any particular amount. I am going to be part of the process myself, and I suppose I have some conflict of interest, but on the other hand, the message that we want to leave with you today is that this is still a very serious disease. The third killer of all diseases in this country and there is still no cure. None. Zero.

We still do not know exactly what causes diabetes. We certainly know about the results. We know about the complications. And I am very proud of Sue and the way she has handled her disease. She lost her right eye just 2 weeks before the kidney surgery. That was not publicized, but she underwent the surgery just 2 weeks before the kidney transplant.

And I would also say to you, as a lot people have mentioned over the years, how courageous it was for me to give a kidney. Not at all. It is the easiest thing I have ever done. Each of you as parents understand what you would do for your children. Her two brothers were also willing to give her a kidney. Fortunately I had told them beforehand that if all things were equal, I would give the kidney simply because, first of all, I did not need a kidney nearly as long as Sue's brothers did. And second, I wanted to. And I think that is a natural parental reaction that any mother or father would do.

I would also indicate to you, that is without doubt the most important thing that I have ever done in my life. Without doubt. Because as I sit here beside her, realizing that my former left kidney is her right kidney and that it has made it possible for her to raise Ali for the last 3½ years, I can think of nothing more important that I have done in my life.

But that is beside the point. It is unfortunate that was necessary. It is unfortunate that thousands of people in this country are waiting for kidney donors, waiting for cadavers, where they do not have living related donors. People are dying of the complications of diabetes because we simply have not laid a hand on the basic cause of the circulation problems, the heart failure, the kidney failures, and the loss of sight among diabetes patients.

So I would hope that we consider, and I say we because I will be part of the deliberations, recognizing how difficult the budget decisions are and the 302(b)'s and Gramm-Rudman-Hollings. This is my 16th budget cycle that I have been involved in. So I want you, my colleagues, to understand I know the problems.

I just hope that in our deliberations we can recognize that although this is not a highly publicized disease compared to others, there are millions and millions of people and their families out there suffering, and that we take this under consideration and recognize that the promise that doctor gave me 20 years ago simply has not been fulfilled, and it should be. Thank you very much.

Senator SPECTER. Thank you, very much, Senator Garn, for your very important testimony. You are really inspirational in the way you present the matter in terms of not only the diabetes issue, but really on the very basic fundamental family value in our society. And your colleagues, as well as all of America, have applauded you and your family and what you have done on the kidney transplants among many other of your activities, so we very much appreciate your testimony. And we look forward to hearing from you in our deliberations on the committee further.

We have been joined by a very distinguished Senator, the first ranking member of the U.S. Senate, I always call him Mr. Chairman from the Judiciary Committee, the Honorable Strom Thurmond, who is here with his wife, Mrs. Nancy Thurmond and their daughter, Julie. They, too, have personal experience on the issue of diabetes. Senator Thurmond, would you care to testify first?

Senator THURMOND. Thank you very much. My wife is going to do the talking.

Senator SPECTER. Well, if you say so, Senator.

Ms. DUCAT. Senator Specter, this is a surprise. Julie is a newly diagnosed diabetic and the Thurmonds are new to diabetes, and the Honorable Senator is cochairing the Search for the Diabetes Genes Initiative and supporting the diabetes effort. And I just wanted to say happy birthday to Julie today.

STATEMENT OF NANCY THURMOND

Senator SPECTER. Well, we welcome you here, Mrs. Thurmond. It is a great pleasure to see you, Nancy, on the Senate premises. We miss you. We know you have been in South Carolina recently. And we welcome you, too, Julie and look forward to your testimony.

Mrs. THURMOND. Thank you very much. Good morning, Mr. Chairman and members of the subcommittee. I am joining Lee Ducat and Senator Garn and his lovely daughter, Sue, today as interested parents of a diabetic child.

Only 8 months ago, when I was a patient at Walter Reed Army Hospital recovering from a triple fracture of my ankle, was our daughter diagnosed as having juvenile diabetes. We had no idea that anything was wrong other than that Julie was looking after me and kept telling me she was very thirsty. And I thought perhaps it was the usual teenage stress and also the hot, humid weather of Washington. But shortly after that she said she really wanted to go to the doctor and Strom and I discovered that Julie has diabetes.

Under ordinary circumstances, the life of a teenager involves adapting to many changes. However, being told that she had diabetes at such a critical time in her development as a young adult has certainly had an impact on Julie and on every member of our family. Strom and I hope for a safe and happy future for Julie, just like the families of the over 12 million other diabetics in America. I am sure that no parent wants their diabetic child to have to live with the burden of continual insulin shots, blood sugar tests, hospital stays, and visits to the doctor's office.

Mr. Chairman, since discovering that Julie was diabetic, we have tried to learn as much as possible about this disease. We have found that there are many efforts being made in the area of research and treatment.

We have been especially impressed with the contribution and role of the Federal Government through the research that is being conducted at the National Institute of Diabetes and Digestive and Kidney Diseases of the National Institutes of Health. The Search for the Diabetes Gene Initiative of the NIDDK promises to make much progress in focusing on the genetic factors that cause diabetes.

As parents, we urge this subcommittee to give careful consideration to providing an appropriate level of funding to support the research activities of the NIDDK. Adequate funding will allow the scientific community to have the ability to discover the genes that produce diabetes, determine the causes, and develop a cure for this disease.

Your interest, Mr. Chairman, in this important issue is most appreciated by the families of those afflicted with diabetes. Thank you, Mr. Chairman, for allowing us to share our views with you this morning.

Senator **Specter**. Thank you very much, Nancy, for your very impressive testimony. We very much appreciate it. Julie, would you have any comment you would like to add? Do you agree with your mother?

Julie **Thurmond**. Yes.

Senator **Specter**. That's fine. Senator Thurmond, do you have any comment you would like to add?

Senator **Thurmond**. I don't have anything to say after she talks.

Senator **Specter**. That reminds me of one of my favorite expressions. I, too, am married to a very lovely, young woman, and I always get in the last word. It is, yes, dear.

Well, thank you very much, Lee Ducat. You have presented a very impressive array of witnesses on behalf of a very important cause. And as usual, you have made a very strong case and we will give very careful consideration to the funding issue. Thank you all very much.

STATEMENT OF DR. PATRICK E. BROOKHOUSER, DIRECTOR OF BOYS TOWN NATIONAL RESEARCH HOSPITAL, OMAHA, NE

Senator **Specter**. I'd like to call now, the next witness, Dr. Patrick Brookhouser, Director of Boys Town National Research Hospital, Omaha, NE. Thank you very much for joining us, Dr. Brookhouser.

Dr. **Brookhouser**. Senator Specter. I serve as director of the Boys Town National Research Hospital in Omaha and I also serve as Father Flannagan, professor and chairman of the Department of Otolaryngology and Human Communication at Creighton University School of Medicine.

Today I am representing the members of the American Society of Pediatric Otolaryngology whose mission is to advance the care provided to children who suffer from disorders of the ear, nose, and throat, as well as related communication problems. I would like to provide testimony this morning regarding the funding requirements of two institutes at the NIH, the National Institute on Deafness and Other Communication Disorders and the National Institute on Child Health and Human Development.

First of all, speaking for those of us who work in the clinical and research areas of communication disorders, I would like to express our sincere gratitude for the efforts of this committee and other Members of the Congress in establishing the National Institute on Deafness and Other Communication Disorders. This has had an electrifying effect on the members of our field. It has focused attention of the public on the problem and it has attracted into our field many, many talented researchers who are now directing their interest toward the problems that are confronting children with these disorders.

Hearing loss is one of the most common disorders suffered by children. Any parent who has been awakened in the middle of the night by a child with an ear infection knows how serious a problem can be and yet, luckily, many of these kids have problems we can correct with medicine and surgery.

But about 1 out of every 1,000 children born suffer from a very severe permanent type hearing loss that is at the present time, not reversible by medical intervention. This number rises to be about 8 to 10 times more prevalent among children who are products of high-risk birth histories and high-risk pregnancies. There is, thankfully, work being done in the field which is addressing itself to the more common causes of these permanent hearing losses. About one-half of these are thought to be hereditary, that is genetically inherited, and until the past year, we have never been able to localize any of the deafness genes.

Luckily, in the past year, two or three of these have now been localized and efforts are proceeding very rapidly toward attempting to clone these genes. One of which is for Ushers syndrome which produces not only deafness, but blindness as well in individuals. This has been discovered for Ushers syndrome, type 2, and efforts are proceeding apace to try to intervene and do something about this serious problem.

Serious infections, like meningitis, of course, continue to take their toll. Ototoxic medications, and finally noise. Unfortunately, much of the hearing loss related to noise is self-inflicted from firecrackers, boom cars, motorcycles, and rock music. Even though the kids themselves are exposing themselves to this, the fact that it is an irreversible loss makes it very, very important that we develop better strategies for preventing the loss and for reversing it, if possible.

I would like to suggest on the part of the American Society of Pediatric Otolaryngology, that we must take advantage of the forward momentum in communication disorders research by providing for the National Institute on Deafness and Other Communication Disorders in the next fiscal year, $165 million of funding.

Turning attention to the NICHD, I would like to say that Pediatric Otolaryngologists are also vitally interested in the areas of low birth rate, infant mortality research, teenage pregnancy, drug abuse in pregnancy, pediatric AIDS, learning disabilities, vaccine development, and sudden infant death syndrome. We would like to also suggest that the Congress provide $635.3 million for the NICHD. This includes $56 million directed toward the growing problem of acquired immunodeficiency syndrome among the pediatric age group.

The abuse of substances among teenage mothers and the results that occur to the infants are just staggering at the present time in the United States. Each of these kids that is born suffers such injury that, in fact, they will be required to get specialized medical and educational intervention for most of their lives and we feel that by efforts directed toward research in these two areas, that we can begin to provide to children some types of intervention that may be able to lessen the burden of these disabilities. Thank you.

PREPARED STATEMENT

Senator **Specter**. Thank you very much, Dr. Brookhouser. We very much appreciate your testimony and we will give very careful consideration to the issues which you have raised.

[The statement follows:]

STATEMENT OF DR. PATRICK E. BROOKHOUSER

Senator Harkin, members of the Committee, ladies and gentlemen, I am Dr. Patrick E. Brookhouser, Director of Boys Town National Research Hospital in Omaha, Nebraska. I also serve as Father Flanagan Professor and Chairman of the Department of Otolaryngology and Human Communication at Creighton University School of Medicine in Omaha. Today I am representing all the members of the American Society of Pediatric Otolaryngology (ASPO), whose mission is to advance the quality of care provided for children in the area of Otolaryngology-Head and Neck Surgery. My purpose is to provide testimony regarding the funding requirements of two Institutes at the National Institutes of Health: the National Institute on Deafness and Other Communication Disorders (NIDCD) and the National Institute on Child Health and Human Development (NICHD).

Pediatric otolaryngologists evaluate and treat children and adolescents with hereditary and acquired disorders of the ear, nose, throat, head and neck. Some of these disorders are present at birth and high-risk newborns are particularly likely to require the services of specialists in our field. Communication disorders and related learning disabilities are among the most challenging disorders affecting the children we serve. Although these problems are seldom life-threatening, they can impose a heavy burden upon the child and his/her family. Communication is the keystone of the learning process. A child with a hearing deficit misses the voices and other sounds that are a normal part of everyday life. A child who cannot speak may face the frustration of not being able to express feelings and needs. While the normal hearing child acquires spoken language with relative ease through listening to others speak, the child with a severe hearing loss must be laboriously taught each word and phrase. A child with a severe learning disability may struggle in frustration attempting to cope with academic subjects which his/her classmates master with ease.

At least one child in a thousand suffers from a hearing loss severe enough to require special educational programming. More than 50% of all profound childhood deafness is hereditary (i.e. genetically transmitted) and no effective medical treatment has yet been developed for the thousands of affected children who are destined to lose some or all of their hearing. Another major cause of profound hearing loss in children is infections (e.g. congenital viruses and childhood meningitis) which, in spite of impressive advances in antimicrobial therapy, continue to deafen thousands of infants and young children each year. An additional group of children lose their hearing because of damage from ototoxic medications, particularly powerful antibiotics and anticancer drugs, which must be used in life-threatening conditions. Research is needed to develop effective methods for minimizing the toxic effects of these therapeutic agents. Much of the noise-related hearing damage among children and adolescents is, unfortunately, self-inflicted by exposure to such noise sources as firearms, rock music, motorcycles and boom cars. The irreversible nature of these noise-induced hearing losses, however, demands that effective and readily accepted means of prevention and treatment be developed.

Infants who are products of high risk pregnancies, many of which are born to teenage mothers, are particularly at-risk for communication disorders and learning disabilities. The all too prevalent phenomenon of alcoholism and other forms of substance abuse among young mothers has added the terms fetal alcohol syndrome and "cocaine babies" to our vocabulary. These infants often require extended periods of costly specialized medical care, and may still suffer severe and permanent neurological disability.

Happily, some progress toward addressing these problems is being made. The establishment of the National Institute on Deafness and Other Communication Disorders was an important milestone along the way toward alleviating the societal burden imposed by childhood communication disorders. The extraordinary efforts and dedication of Dr. Jay Moskowitz during his tenure as Acting Director of the NIDCD have paved the way for the newly appointed permanent Director, Dr. James Snow. The NIDCD is fortunate to have recruited Dr. Snow, an otolaryngologist who is both administratively skilled and highly respected as a scientist. He has set about implementing the legislative mandates for the Institute and fashioning programs to address the needs identified in the NIDCD's National Strategic Research Plan.

In the arena of public education, the NIDCD co-sponsored an NIH Consensus Development Conference on Noise and Hearing Loss. A panel of experts, which I was honored to chair, heard a day and a half of presentations detailing the state of current knowlege in this important area. The consensus statement issued at the conclusion of the meeting stressed the need for greater public health efforts aimed at preventing this needless type of hearing loss as well as specific research initiatives which should be pursued. The high level of national media attention given to the conference reflects public concern about preventing hearing loss, particularly among young people.

Establishment of the NIDCD has engendered excitement among researchers and clinicians alike, as reflected in a marked increase in the number of grant applications being received and considered by the Advisory Council. Even more encouraging is the actual research progress being made in specific areas, such as hereditary hearing loss. The first step in developing strategies for preventing and treating genetic disorders is to locate the specific gene(s) involved. Patients with Usher Syndrome, a particularly devastating disorder, suffer severe to profound hearing loss and gradual loss of vision due to retinitis pigmentosa. During the past year, the gene which is responsible for one type of Usher Syndrome has been localized to a particular chromosome. Additional studies are already underway aimed at cloning the gene. The chromosomal location of the gene for another hereditary hearing loss syndrome, Waardenberg, has also been determined. These findings represent the first ray of hope for families with children who suffer from these disorders.

To maintain the forward momentum in communication disorders' research and research training, which has resulted from the establishment of the NIDCD, it is essential that adequate funds be made available to the Institute for both intramural and extramural programs. The American Society for Pediatric Otolaryngology requests approval of $165,000,000 for the National Institute on Deafness and Other Communication Disorders for FY 1991.

Turning attention to the National Institute on Child Health and Human Development, pediatric otolaryngologists are vitally interested in the research and training initiatives of the NICHD in the areas of low birth weight/infant mortality, teenage pregnancy, drug abuse in pregnancy, pediatric aids, learning disabilities, childhood injury prevention, vaccine development and sudden infant death syndrome. The FY 1991 Professional Judgment Budget for NICHD reiterates two general aims: to remedy current budget problems and to increase resources for specific Institute initiatives. We appreciate the outstanding leadership which NICHD Director Dr. Duane Alexander has continued to provide during a challenging period from a budgetary viewpoint.

Current budget problems include unacceptable downward negotiations for research project grants (RPGs) and center grants, the low funding rate of RPGs, inadequate numbers of research training positions and insufficient funds for continuation and expansion of vital research and development contract programs. For example, the FY 1991 President's Budget supports 1,069 noncompeting RPGs and 362 new and competing RPGs at downward negotiations of 15.5 percent and 12.0 percent, respectively. An additional $42,357,000 has been included in the Professional Judgment Budget to eliminate these cuts. Further, $59,073,000 has been included to fund 282 additional competing research project grants, thereby increasing the funding rate from 22.5 percent under the President's Budget to 40.0 percent under the Professional Judgment Budget. The impact on ongoing research would be significant, allowing expansion of the NICHD's major research programs. Funds have also been requested for expansion of research within the Institute's cooperative clinical research networks. In addition, funds have been included to begin a cooperative clinical network for studies related to sudden infant death syndrome.

The American Society of Pediatric Otolaryngology requests approval of funding in the amount of $635.3 million for the National Institute of Child Health and Human Development during FY 1991. This amount includes $56 million dollars in funding for the growing problem of Acquired Immunodeficiency Syndrome among the pediatric age group.

Senator **Specter**. It is now 10 o'clock and we are scheduled to have a vote at this time, and as I had announced earlier, I am scheduled to testify before the Foreign Relations Committee, so we will stand in recess for hopefully not more than 20 minutes. Thank you.

[Pause.]

STATEMENT OF MARCIA R. BOYD, SOCIETY OF NUCLEAR MEDICINE

Senator **Specter**. The vote was postponed. We will now call Ms. Marcia Boyd, the Society of Nuclear Medicine. We welcome you, please proceed with your statement.

Ms. **Boyd**. The Society of Nuclear Medicine-technologist section strongly urges a significant increase from fiscal year 1990 appropriations to the allied health project grants and contracts. The society is a scientific organization of over 10,000 members, including 5,000 members of the technologists section.

Nuclear medicine is the medical specialty that uses small amounts of radioactive materials for diagnostic and therapeutic procedures. Each year there are over 7 million nuclear medicine imaging examinations performed on the patient and millions of exams on specimens of body fluids and tissues. The nuclear medicine technologist [NMT], under the supervision of a physician, directs or participates in the daily operation of the nuclear medicine department. The responsibilities of the NMT are varied and include: preparing and administering radiopharmaceuticals; positioning patients for imaging procedures; interacting with patients; operating nuclear medicine equipment; maintaining radiation safety; analyzing biologic specimens and computer data analysis and performing quality control measurements.

The decline in the number of allied health professionals, compounded by an increased demand, has created a crisis situation in the American health care system that threatens access to quality medical care. This crisis is also apparent in the field of nuclear medicine as hospitals and training programs have been unable to achieve their goals in recruitment and retention efforts for qualified nuclear medicine technologists at a critical time when the available technology has greatly enhanced diagnostic and therapeutic capabilities.

Data—for the academic year 1987-88—from the Committee on Allied Health Education and Accreditation [CAHEA] for nuclear medicine technology indicates that there are 106 programs operating at 63 percent capacity, a decrease of 25 percent from the peak year in 1985 when 141 schools were accredited. The Nuclear Medicine Technology Certification Board [NMTCB] reported that in the period 1985-89 there has been a 25-percent decrease in the number of students taking and passing its examination. Ultimately, decreases in enrollees and prospective examinees result in fewer practitioners.

The technologist section conducted a survey in 1987 to determine the impact of the prospective payment system [PPS] on the delivery of nuclear medicine services. Over 34 percent of the respondents required more than 3 months to fill a technologist position. Forty-three percent of the respondents indicated that there had been a decrease in the supply of nuclear medicine technologists in their area. In regards to the perception of the supply of nuclear medicine technologists in their geographic area, 57 percent of the respondents perceived a shortage as compared to 19 percent in 1984 in the technologist section's human resource survey. The June 1988 Institute of Medicine study reported that jobs for the NMT will increase 23 percent by the year 2000. Eighty-nine percent of the respondents perceived a shortage of NMT's in a 1988 survey by the American Healthcare Radiology Administrators.

With the advent of the prospective payment system in 1983, cost control has become a decisive factor in hospital management. Changes in reimbursement have contributed to the shortage of qualified nuclear medicine technologists by the closing of hospital based programs which are recorded as nonrevenue producing and a shift in utilization from inpatient to outpatient diagnostic imaging centers. Technological changes have resulted in an increase in the number and complexity of nuclear medicine procedures being performed. Nuclear medicine exams are a cost-effective means of providing patient care and in the ever present arena of cost control will even be more heavily utilized in the future.

The technologist section of the Society of Nuclear Medicine has been active in developing and implementing recruitment strategies that promote and market nuclear medicine technology as a career such as public relations activities, that is, videotapes, brochures, lectures, and the development of scholarship funds. However, Federal assistance is necessary to aid individual educational programs in implementing their own recruitment efforts. In addition, Federal assistance is needed to help nuclear medicine schools recruit and retain qualified faculty. The technologists section is offering assistance in this area by sponsoring workshops each year for educators, focusing on topics such as clinical evaluation, curriculum development, and current issues such as faculty development and retention.

As quality of care and access to health care are dominant themes in the health care delivery system, consideration must be given to the implications of the decreased number of nuclear medicine technologists. Specifically, as the patient population ages, more nuclear medicine will be performed to detect cancer, neurological diseases, and cardiac diseases. In addition, as new radiopharmaceuticals and advanced imaging modalities are introduced into the clinical setting and practice, NMT's will require additional training in order to perform the more complex procedures. This may lengthen the time required to perform procedures, resulting in the need for additional technologists. The current shortage of NMT's aggravates this problem, and if allowed to persist, will severely curtail the provision of critical medical services.

PREPARED STATEMENT

The Society of Nuclear Medicine-technologist section believe that the manpower shortage is the greatest issue currently facing nuclear medicine technology. An immediate response to this problem must be forthcoming. We strongly recommend that funding for the fiscal year 1991 allied health project grants and contracts be increased to a level that will remedy the current manpower dilemma and deter a potentially more serious manpower shortage in the future.

Senator SPECTER. Thank you very much, Ms. Boyd. We appreciate your testimony. We will give very careful consideration to your requests.

[The statement follows:]

STATEMENT OF MARCIA R. BOYD

The Society of Nuclear Medicine-Technologist Section strongly urges a significant increase from Fiscal Year 1990 appropriations to the Allied Health Project Grants and Contracts. The Society is a scientific organization of over 10,000 members, including 5,000 members of the Technologists Section.

Nuclear medicine is the medical specialty that uses small amounts of radioactive materials for diagnostic and therapeutic procedures. Each year there are over 7 million nuclear medicine imaging examinations performed on the patient and millions of exams on specimens of body fluids and tissues. The nuclear medicine technologist (NMT), under the supervision of a physician, directs or participates in the daily operation of the nuclear medicine department. The responsibilities of the NMT are varied and include: preparing and administering radiopharmaceuticals; positioning patients for imaging procedures; interacting with patients; operating nuclear medicine equipment; maintaining radiation safety; analyzing biologic specimens and computer data analysis and performing quality control measurements.

The decline in the number of allied health professionals, compounded by an increased demand, has created a crisis situation in the American health care system that threatens access to quality medical care. This crisis is also apparent in the field of nuclear medicine as hospitals and training programs have been unable to achieve their goals in recruitment and retention efforts for qualified nuclear medicine technologists at a critical time when the available technology has greatly enhanced diagnostic and therapeutic capabilities.

Data (for the academic year 1987-1988) from the Committee on Allied Health Education and Accreditation (CAHEA) for nuclear medicine technology indicates that there are 106 programs operating at 63% capacity, a decrease of 25% from the peak year in 1985 when 141 schools were accredited. The Nuclear Medicine Technology Certification Board (NMTCB) reported that in the period 1985 - 89 there has been a 25% in the number of students taking and passing its examination. Ultimately, decreases in enrollees and prospective examinees result in fewer practitioners.

The Technologist Section conducted a survey in 1987 to determine the impact of the Prospective Payment System (PPS) on the delivery of nuclear medicine services. Over 34% of the respondents required more than three months to fill a technologist position. Forty-three percent (43%) of the respondents indicated that there had been a decrease in the supply of nuclear medicine technologists in their area. In regards to the perception of the supply of nuclear medicine technologists in their geographic area, 57% of the respondents perceived a shortage as compared to 19% in 1984 in the Technologist Section's Human Resource Survey. The June 1988 Institute of Medicine study reported that jobs for the NMT will increase 23% by the year 2000. Eighty-nine percent of the respondents perceived a shortage of NMT's in a 1988 survey by The American Healthcare Radiology Administrators.

With the advent of the Prospective Payment System in 1983, cost-control has become a decisive factor in hospital management. Changes in reimbursement have contributed to the shortage of qualified nuclear medicine technologists by the closing of hospital based programs which are recorded as non-revenue producing and a shift in utilization from inpatient to outpatient diagnostic imaging centers. Technological changes have resulted in an increase in the number and complexity of nuclear medicine procedures being performed. Nuclear medicine exams are a cost effective means of providing patient care and in the ever present arena of cost control will even be more heavily utilized in the future.

The Technologist Section of the Society of Nuclear Medicine has been active in developing and implementing recruitment strategies that promote and market nuclear medicine technology as a career such as public relations activities, i.e. videotapes, brochures, lectures and the development of scholarship funds. However, Federal assistance is necessary to aid individual educational programs in implementing their own recruitment efforts. In addition, Federal assistance is needed to help nuclear medicine schools recruit and retain qualified faculty. The Technologists Section is offering assistance in this area by sponsoring workshops each year for educators, focusing on topics such as clinical evaluation, curriculum development, and current issues such as faculty development and retention.

As quality of care and access to health care are dominant themes in the health care delivery system, consideration must be given to the implications of the decreased number of nuclear medicine technologists. Specifically, as the patient population ages, more nuclear medicine will be performed to detect cancer, neurological diseases and cardiac diseases. In addition, as new radiopharmaceuticals and advanced imaging modalities are introduced into the clinical setting and practice, NMTs will require additional training in order to perform the more complex procedures. This may lengthen the time required to perform procedures, resulting in the need for additional technologists. The current shortage of NMT's aggravates this problem, and if allowed to persist, will severely curtail the provision of critical medical services.

The Society of Nuclear Medicine-Technologist Section believe that the manpower shortage is the greatest issue currently facing nuclear medicine technology. An immediate response to this problem must be forthcoming. We strongly recommend that funding for the Fiscal Year 1991 Allied Health Project Grants and Contracts be increased to a level that will remedy the current manpower dilemma and deter a potentially more serious manpower shortage in the future.

Senator SPECTER. They have now started the vote, so we will stand in recess. I think I will be able to return at 10:30. Thank you all very much.

[A brief recess was taken.]

STATEMENT OF DENNIS KELLEY, SECRETARY, NATIONAL FUEL FUNDS NETWORK, PHILADELPHIA, PA

Senator SPECTER. We will resume the hearing, ladies and gentlemen. I, again, apologize for the delay and would like to call now on Dennis Kelley from the Philadelphia-based National Fuel Funds Network. Welcome, Mr. Kelley. Your full statement will be made a part of the record, and we look forward to your testimony.

Mr. KELLEY. Thank you, sir. I would like to thank you for this opportunity to testify in support of restoring funding for the Low-Income Home Energy Assistance Program, to a minimum level of $2 billion for fiscal year 1991.

The National Fuel Funds Network, which I represent, has over 100 members, including private fuel funds and other concerned groups from two-thirds of the States. As community-based organizations providing emergency, energy assistance to our country's neediest citizens, we have seen firsthand the serious consequences of reductions in Federal funding for LIHEAP. Our fundraising efforts contribute $31 million annually as a critical LIHEAP supplement, yet this effort falls short of the 33-percent cuts experienced since

1985 and the proposed $340 million reduction currently threatening the over 200,000 needy households we serve.

The administration has testified before the House Human Resources Subcommittee, that the poor spend only 3.9 percent of their income on heating, and that energy costs are no longer a burden to low-income households. These figures would indicate that a family surviving on $500 per month, would pay only $19.50 per month for heat. This estimate, in our experience, bears no relationship to reality. We remain painfully aware that our clients devote 15 percent of their income to energy bills, four times what the typical, middle income family must do. For the poorest of the poor, the burden is even higher. Many of our members report that up to one-third of their client's incomes go to home energy cost.

In the wake of Federal funding cuts, many States have reduced the average LIHEAP grant and tightened eligibility requirements. In Missouri, my State, the average LIHEAP grant is now only $200. In fiscal year 1989, increased eligibility requirements removed an estimated 10,000 Missouri households, 60 percent of which contained at least one elderly or disabled person.

In regards to the personal consequences of Federal funding cuts, many hundreds of thousands of low income families suffer termination of their heat source, and daily face life threatening hardships. In Philadelphia, the absence of home heating this winter contributed to house fires which claimed the lives of children. In rural Missouri, rising propane prices have deprived elderly residents of basic life necessities, as well as their personal dignity.

The NFFN believes that such situations will become more severe if Federal energy assistance resources shrink further. We are committed to sustaining the public-private partnership needed to address the energy, poverty crisis we face. But, if we are to preserve any kind of a meaningful safety net, the withdrawal of the Federal Government as a partner must cease.

While we appreciate that the Senate has previously supported LIHEAP, we must again ask for your help. We respectfully recommend that LIHEAP funding in fiscal 1991 be restored to a minimum of $2 billion as a matter of humane and sound public policy.

Thank you, sir.

Senator SPECTER. Thank you very much, Mr. Kelley. We struggled very hard on LIHEAP last year. We added considerably to the figure which was put forward by the administration, and it is a very difficult matter, as this room is filled with witnesses testifying about very many important subjects, and there are many, many more. I think there is no subcommittee which wrestles with more problems than does this one on health, human services, education, and labor. We have a very, very small sum of money to allocate in many, many directions.

When we talk about low-income home energy assistance, we deal very much in the abstract, and I think it would be useful to talk in more concrete terms as to precisely what it means, what you were not able to do this winter as a result of the funding. You made a couple of specific references to Philadelphia and to St. Louis. I know the organization is based in Philadelphia and you are from St. Louis, but I think it would be useful if you would provide some specific illustrations as to how many people could not have heat, not only specific anecdotal materials, because the generalizations do not really tell enough.

We are about to have a big debate with SLIAG, SLIAG, and LIHEAP and all the other alphabet soups you can think of. The more specific you can be, the more useful it is for those of us who are pushing this cause, and I am an advocate for LIHEAP as you know.

PREPARED STATEMENT

Mr. **Kelley**. We appreciate your efforts. We have recently begun to try to document, not only the anecdotal stories. We sort of refer to those people as those who have fallen through the crack and are needlessly suffering, and if we might, we try to continue that effort and try to share them with your staff.

Senator **Specter**. I think you ought to give us more information. The harder hitting, the more factual, the more detailed, the better.

Mr. **Kelley**. Thank you, sir.

[The statement follows:]

STATEMENT OF DENNIS KELLEY

THANK YOU FOR THE OPPORTUNITY TO SUBMIT THIS TESTIMONY, SUPPORTING RESTORATION OF FUNDING FOR THE LOW INCOME HOME ENERGY ASSISTANCE PROGRAM (LIHEAP) IN FY 1991 TO THE MINIMALLY-ADEQUATE LEVEL OF $2 BILLION.

THE NATIONAL FUEL FUNDS NETWORK (NFFN) IS A MEMBERSHIP ORGANIZATION COMPRISED OF OVER 100 DUES-PAYING REPRESENTATIVES OF PRIVATE FUEL FUNDS, COMMUNITY ACTION AND OTHER SOCIAL SERVICE ORGANIZATIONS, UTILITIES, REGULATORS AND OTHERS, FROM TWO-THIRDS OF THE STATES. THUS, WE REPRESENT A NATIONAL, GRASS-ROOTS LEVEL PERSPECTIVE ON THE DIMENSIONS OF THE ENERGY/POVERTY PROBLEM. OUR MEMBERS SHARE A COMMITMENT TO INCREASING THE FINANCIAL AND HUMAN RESOURCES AVAILABLE TO ADDRESS THE ENERGY NEEDS OF LOW-INCOME HOUSEHOLDS. THE NFFN HAS BEEN IN EXISTENCE FOR SIX YEARS, SERVING AS A CLEARINGHOUSE FOR INFORMATION EXCHANGE AND TECHNICAL ASSISTANCE FOR THE ONE HUNDRED PLUS PRIVATE FUEL FUNDS THAT HAVE DEVELOPED IN RECENT YEARS, IN AN EFFORT TO SUPPLEMENT INADEQUATE LIHEAP FUNDING AT THE LOCAL LEVEL.

AS PRIVATE SECTOR, COMMUNITY-BASED EFFORTS TO PROVIDE LAST RESORT EMERGENCY ENERGY ASSISTANCE TO SOME OF OUR COUNTRY'S NEEDIEST AND MOST VULNERABLE CITIZENS, WE HAVE SEEN FIRST-HAND THE SERIOUS, NEGATIVE CONSEQUENCES OF ONGOING REDUCTIONS IN FEDERAL FUNDING FOR LIHEAP. ACCORDING TO A SURVEY WE CONDUCTED IN COOPERATION WITH THE EDISON ELECTRIC INSTITUTE AND THE AMERICAN GAS ASSOCIATION, OUR PRIVATE SECTOR FUNDRAISING EFFORTS CONTRIBUTE AT LEAST $31 MILLION ANNUALLY AS A CRITICAL SUPPLEMENT TO LIHEAP FUNDING ON BEHALF OF NEARLY 200,000 HOUSEHOLDS; YET THIS IS FAR FROM EVEN APPROACHING CLOSING THE GAP LEFT BY RECENT YEAR'S DRASTIC FEDERAL FUNDING CUTS. THIS DOES, HOWEVER, INDICATE STABILITY IN THE PRIVATE SECTOR'S CONTRIBUTION DURING YEARS WHEN--BY CONTRAST--THE FEDERAL GOVERNMENT HAS SLASHED FUNDING BY 33% SINCE FY 1985.

THE DOLLAR-HELP PROGRAM IN ST. LOUIS WAS FOUNDED IN 1982 BY MY SISTER, THE LATE SISTER PATRICIA ANN KELLEY, TO PROVIDE ENERGY ASSISTANCE TO HELP VERY POOR HOUSEHOLDS WHO HAVE EXHAUSTED ALL AVENUES OF PUBLIC AID. IN FISCAL 1989, DOLLAR-HELP RAISED AND DISTRIBUTED OVER $430,000 AND SERVED OVER 2,200 ELDERLY AND NEEDY HOUSEHOLDS. SINCE ITS INCEPTION, DOLLAR-HELP HAS RAISED MORE THAN

$2.7 MILLION FROM PRIVATE CONTRIBUTIONS AND PROVIDED HEATING ASSISTANCE TO NEARLY 12,000 HOUSEHOLDS IN NINE COUNTIES OF EASTERN MISSOURI. AS PROUD AS WE ARE OF THE DOLLAR-HELP PROGRAM, WE ARE AWARE OF WHAT SISTER PAT SAID SO OFTEN, THAT THE MONEY RAISED BY PRIVATE FUNDS LIKE DOLLAR-HELP IS JUST A DROP IN THE BUCKET WHEN COMPARED WITH THE ASSISTANCE ANNUALLY PROVIDED BY LIHEAP. IN THIS PERSPECTIVE, THERE IS NO WAY THAT DOLLAR-HELP, OR EVEN THE COMBINED EFFORTS OF ALL OUR MEMBER FUEL FUNDS, CAN MAKE UP THE ADMINISTRATION'S PROPOSED $340 MILLION REDUCTION IN LIHEAP FUNDING THREATENING THE LIFE AND HEALTH OF THE CLIENTS WE SERVE.

WHILE WE HAVE FOUND THAT THERE ARE MANY GENEROUS INDIVIDUALS WHO CONTRIBUTE A FEW DOLLARS, OR MORE, EVERY YEAR TO HELP THEIR LESS FORTUNATE NEIGHBORS, WE ALSO FIND THAT MANY POTENTIAL CONTRIBUTORS--INDIVIDUALS AND CORPORATIONS ALIKE--WANT TO KNOW WHY GOVERNMENT IS NOT FULFILLING ITS RESPONSIBILITY TO SUPPORT AN ADEQUATELY-FUNDED LIHEAP? WE CAN RESPOND TO THIS VERY REAL AND LEGITIMATE CONCERN ONLY BY BRINGING IT DIRECTLY TO YOUR ATTENTION.

THE ADMINISTRATION TESTIFIED ON FEBRUARY 1, 1990, BEFORE THE HOUSE HUMAN RESOURCES SUBCOMMITTEE THAT THE POOR SPEND ONLY 3.9% OF THEIR INCOME ON HEATING, AND THAT ENERGY COSTS ARE NO LONGER BURDENSOME TO LOW-INCOME HOUSEHOLDS. THE ADMINISTRATION'S FIGURES WOULD INDICATE THAT A HOUSEHOLD WITH AN INCOME OF $500/MONTH WOULD PAY ONLY $19.50/MONTH ON AN ANNUAL BASIS FOR HEAT. THIS ESTIMATE, IN OUR EXPERIENCE, BEARS NO RELATIONSHIP TO REALITY. WE REMAIN PAINFULLY AWARE THAT THE PEOPLE WE SERVE STILL HAVE TO DEVOTE 15% OF THEIR INCOME TO COVER THEIR ENERGY BILLS--FOUR TIMES WHAT THE TYPICAL MIDDLE-INCOME FAMILY MUST DO. FOR THE POOREST OF THE POOR, THE BURDEN IS EVEN HIGHER! MANY OF OUR MEMBER FUEL FUNDS REPORT IT WOULD TAKE ONE-THIRD OF THEIR CLIENTS' INCOMES TO COVER ESSENTIAL HOME ENERGY COSTS--CLEARLY AN IMPOSSIBLE BURDEN. A STUDY BY THE NATIONAL CONSUMER LAW CENTER, "ENERGY AND THE POOR: THE FORGOTTEN CRISIS", SUPPORTS OUR ESTIMATES OF THE PROPORTION OF LOW-INCOME FAMILIES' INCOMES SPENT ON HEATING. WHAT, THEN, ARE THE RESULTS LOCALLY?

IN THE WAKE OF FEDERAL FUNDING CUTS SINCE FY 1985, MANY STATES HAVE REDUCED THE AVERAGE LIHEAP GRANT AND TIGHTENED THE ELIGIBILITY REQUIREMENTS. IN MISSOURI, THE AVERAGE LIHEAP GRANT HAS BEEN DE-

CREASED FROM $250 IN FY 1987 TO ABOUT $200 IN FY 1990. IN FY 1989, MISSOURI INCREASED THE LIHEAP ELIGIBILITY REQUIREMENTS, THEREBY REMOVING AN ESTIMATED 10,000 ELIGIBLE HOUSEHOLDS FROM THE PROGRAM. OF THE HOUSEHOLDS REMOVED, 60% CONTAINED AT LEAST ONE ELDERLY OR DISABLED PERSON.

WE HAVE BEGUN TO DOCUMENT THE EVEN MORE SEVERE PERSONAL CONSEQUENCES OF FEDERAL FUNDING CUTS. DUE TO THEIR INABILITY TO PAY ENERGY COSTS BY THEMSELVES OR WITH THE MINIMAL ASSISTANCE AFFORDED BY LIHEAP, MANY HUNDREDS OF THOUSANDS OF LOW-INCOME FAMILIES SUFFER TERMINATION OF THEIR HEAT AND UTILITY SERVICES, OR LOSS OF OTHER HEATING AND FUEL SUPPLIES. YOU CAN WELL-IMAGINE THE LIFE AND HEALTH-THREATENING HARDSHIPS THAT CAN RESULT.

IN PHILADELPHIA THERE HAVE BEEN AT LEAST THREE MAJOR, WIDELY-PUBLICIZED TRAGEDIES INVOLVING THE ABSENCE OF HOME HEATING THIS WINTER WHICH HAVE RESULTED IN THE DEATHS OF THREE ADULTS AND FIVE YOUNG CHILDREN. REACTING TO ONE OF THE RECENT FIRES, THE NEXT-DOOR NEIGHBOR OFFERED A CHILLING EULOGY: "THEY WERE GOOD NEIGHBORS. THE ONLY PROBLEM THEY HAD WAS, THEY WERE POOR AND THEY DIDN'T HAVE NO HEAT."

IN RURAL MISSOURI, PROPANE PRICES HAVE TRIPLED, THE INCREASES EATING UP THE SOCIAL SECURITY MONEY THAT ONE ELDERLY RESIDENT HAD EARMARKED FOR OTHER BASIC LIFE NECESSITIES. IN THE FACE OF THE LARGE BILL SHE EXPECTS AND THE SACRIFICES IT WOULD IMPOSE, SHE COMMENTED WITH TYPICAL MIDWESTERN PRACTICALITY THAT "I'VE GOT TO HAVE HEAT, SO THAT WILL HAVE TO COME FIRST." AND SHE IS NOT ALONE. ONE SOCIAL WORKER SADLY REPORTED THAT, IN A RURAL AREA "I RAN INTO A WOMAN LIVING IN SUCH A COLD, POORLY-HEATED HOUSE THAT SHE HAD TO TAKE HER DOG TO BED FOR NEEDED WARMTH."

THE LOSS OF SERVICE CAN ALSO RESULT IN FAR TOO MANY CASES OF ABANDONMENT OF PROPERTIES, WITH ITS CONCOMITANT DETERIORATION OF NEIGHBORHOODS AND CITIES AS A WHOLE. A 1989 EDITORIAL IN THE MILWAUKEE JOURNAL CITED THAT MORE THAN 5,000 FAMILIES IN THE MILWAUKEE AREA ALONE HAVE DOUBLED OR TRIPLED UP IN HOUSING BECAUSE OF SHRINKING INCOMES AND RISING EXPENSES, INCLUDING HIGH HEATING BILLS. MANY OF THOSE FAMILIES EITHER GO WITHOUT HEAT OR TRY TO KEEP WARM WITH WHATEVER MEANS ARE AVAILABLE, FORCING THEM, IN THE

WORDS OF A WISCONSIN PUBLIC SERVICE COMMISSIONER, "TO FACE THE RISK OF LOSING LIFE TO WINTER'S BITTER COLD OR THE HORRORS OF ACCIDENTAL FIRE."

THE NFFN BELIEVES THAT THE FURTHER EXACERBATION OF THIS DIRE SITUATION THAT WILL UNDOUBTEDLY RESULT FROM FURTHER SHRINKAGE OF FEDERAL ENERGY ASSISTANCE RESOURCES, IS SIMPLY, UNACCEPTABLE. WE IN THE PRIVATE SECTOR ARE COMMITTED TO SUSTAINING OUR PUBLIC/PRIVATE PARTNERSHIP EFFORTS LOCALLY, TO PROVIDE NECESSARY SUPPLEMENTS TO GOVERNMENT FUNDING. MANY OF US HAVE HELPED ENSURE THAT STATES USE OIL OVERCHARGE FUNDS (WHICH ARE NOW VIRTUALLY DEPLETED), AND EVEN STATE REVENUES, SIMILARLY TO SUPPLEMENT LIHEAP DOLLARS. WE AGREE THAT AT THE LOCAL AND STATE LEVELS, WE MUST BE PARTNERS IN THE EFFORT TO PROVIDE THE NECESSARY RESOURCES TO ADDRESS EFFECTIVELY THE PERSISTENT AND COMPLEX ENERGY/POVERTY CRISIS WE FACE IN THIS COUNTRY. BUT, IF WE ARE TO PRESERVE ANY KIND OF MEANINGFUL ENERGY SAFETY NET FOR OUR MOST VULNERABLE CITIZENS, THE WITHDRAWAL OF THE FEDERAL GOVERNMENT AS A PARTNER IN THIS EFFORT MUST CEASE, AND INDEED, MUST BEGIN TO REVERSE ITSELF. THE OVER $340 MILLION REDUCTION IN FY 1991 FUNDING PROPOSED BY THE ADMINISTRATION IS UNTHINKABLE.

WHILE WE APPRECIATE ALL THAT HAS BEEN DONE IN THE SENATE IN SUPPORT OF LIHEAP LAST YEAR, WE MUST AGAIN ASK FOR YOUR HELP. IN ACCORDANCE WITH RESOLUTIONS PREVIOUSLY ADOPTED UNANIMOUSLY BY OUR MEMBERSHIP, AS WELL AS ACTION TAKEN BY OUR BOARD OF DIRECTORS, WE RESPECTFULLY BUT URGENTLY COMMEND TO YOU RESTORATION OF LIHEAP FUNDING IN FY 1991 TO THE RANGE OF $2 BILLION, AS A MATTER OF HUMANE, FAIR AND SOUND PUBLIC POLICY. THANK YOU FOR YOUR CAREFUL CONSIDERATION OF THIS TESTIMONY.

STATEMENT OF GERALDINE DIETZ FOX, EXECUTIVE DIRECTOR, FRIENDS OF NIDCD, INC.

ACCOMPANIED BY RACHEL DUBIN

Senator SPECTER. Thank you. I would now like to call on a distinguished Pennsylvanian, Ms. Geraldine Dietz Fox, who has done an outstanding job in advocacy for the deaf. Ms. Fox has patrolled the congressional halls, which has made a very major impact, and has gotten some very good results for her cause. We welcome you here, Gerry, and look forward to your testimony.

Ms. FOX. Thank you very much, Senator Specter and members of the staff. It is indeed a pleasure for me to be here again to testify. There will never be enough praises or words of thanks to all of you for what you have done for your genuine concern and your support, and we have moved quickly to meet the challenges that you have entrusted to us.

This year, NIDCD will fund 426 grants, 122 training grants, 5 research and developments, and 3 to 4 centers. We have also appointed our first director, established the advisory council, the board, and we are grateful to have had the expertise of Dr. Jay Moskowitz to guide us first, and now we have a very brilliant gentleman from Philadelphia that comes straight to us as our director, from the University of Pennsylvania Hospital, where he was chairman of the Human Communications Department.

Our researchers are eager to continue the momentum that you have inspired us. One of our researchers, Dr. Josef Miller, in Ann Arbor, MI, at the Kresge Hearing Research Institute, has told me that his researchers are so excited that they are coming to the lab 7 days a week. We have already had a tremendous breakthrough, the first gene for a hereditary cause of deafness, Ushers syndrome, type 2, was identified and located by the investigators at Boys Town National Institute in Omaha, NE. These findings substantiate that the methodology is now in place to vigorously pursue genetic causes of hearing impairment and deafness.

Let our researchers help lower that $30 billion that it costs our Government for medical services and rehabilitative services. This is not the time for NIDCD to plateau. Our level of excellence must continue. How grateful we are to you for having given us this wonderful beginning.

Now, we need to keep the funding at a level that would allow us not only to maintain our present programs, but to progress and expand. Therefore, Senator Specter and members of the subcommittee, I respectfully request $165 million for NIDCD for fiscal year 1991.

PREPARED STATEMENT

Let us resolve now to put our energies and resources into the hope of the future, and into the promise of a more productive quality of life for our children, their children and all generations.

Senator SPECTER. Thank you very much, Ms. Fox. We will give your testimony very, very careful consideration. Your full statement will be made a part of the record, and in our evaluation, we will do the very best that we can.

[The statement follows:]

STATEMENT OF GERALDINE DIETZ FOX

Good morning, Senator Harkin and Members of the Subcommittee. My name is Geraldine Dietz Fox. I want to thank you for allowing me to testify once again. It's hard to believe that this is my 4th appearance before you as we work together to search for preventions, causes, and cures for all the communication disorders. These discoveries will insure a better quality of life for 33 million Americans who suffer disorders of hearing, balance, speech, language, voice, taste, smell and touch.

As Executive Director of Friends of the National Institute on Deafness and Other Communication Disorders (Friends of NIDCD), I am here representing 2 1/2 million members of organizations and individuals who support expanded development of research and training for the NIDCD.

Congress has been generous to its newest Institute. There will never be enough praises or words of thanks for your genuine concern and support of our endeavor over these past few years.

We, in turn, are aware of the seriousness of our responsibilities to meet the challenges you have entrusted to our care, and we have moved quickly to fulfill your mandates.

I am happy to report that during this past year (NIDCD's first full year in operation), the Institute appointed its first Director, Advisory Board (I was elected Chairperson at its first meeting in June, 1989), Advisory Council and capable administrative and support Staffs. We were indeed fortunate to have had the wisdom and guidance of Acting Director, Dr. Jay Moskowitz, for almost a year and a half.

The distinguished Otorhinolaryngologist, Dr. James B. Snow, Jr., our new Director, was selected from over 20 of our country's most able candidates. Dr. Snow has an outstanding reputation as a clinician and researcher, and has gained the respect of his colleagues all over the world. We are delighted to have a man of his caliber to lead us.

Because of your strong commitment to us in FY'90, this year NIDCD hopes to award 426 research grants, 3-4 research centers, 122 research training grants, and 5 research and development contracts.

One of NIDCD's most important challenges is to address the critical shortage of researchers within the communication disorders field. Our goal is to attract investigators with diverse professional backgrounds in order to build a cadre of future scientists. Physicians, clinicians, and researchers with expertise in such areas as physics, engineering, computer science, molelecular biology, and molecular genetics are a recruitment priority. These will include pre-doctoral and post-doctoral students.

NIDCD expects to recruit under-represented minority candidates for research and clinical training. High school and college students showing promise in mathematics, science, and engineering will be encouraged to enter the communication disorder field through participation in summer programs.

One of the most exciting avenues of research at NIDCD is the advancement in technology of assistive devices for the communication disorders. I was deeply touched by a story I heard recently about a 5 year-old child who lost the hearing in both her ears at age 2. Some time after this little girl was fitted with a cochlear implant, the mother heard a ruckus upstairs where she had gone to play. The mother investigated and found her daughter stomping around the floor with great gusto. "What are you doing?" asked the mother. "I'm listening to my feet!" the child enthused.

Other technological advancements are equally impressive. Did you know, for instance, that it is possible to diagnose hearing impairment in a baby within a few minutes after birth? An infant can be fitted with hearing aids when they are several weeks old and (because of these factors) speech, language, and auditory stimulation for a child can actively begin during this most crucial learning period. We hope that, within the next decade, **all** high-risk infants will be tested for hearing acuity.

Other areas identified as needing crucial attention within the communication disorders fields are:

1) regeneration of hair cells and neural tissue

2) genetics--identification of the genes that carry deafness, balance, voice, speech, language, taste and smell disorders

3) epidemiology--the occurrence and distribution of a disorder

4) childhood diseases, such as otitis media which primarily affect children and cause a loss in hearing

5) the advancement of better assistive devices, including hearing aids and cochlear implants

6) balance disorders

7) speech and language problems in normal hearing and deaf children and adults

8) voice disorders

9) neurobiology of the chemical senses--elderly people can suffer from serious malnutrition because they can't taste or smell food

10) education about environmental factors causing communication disorders (It is estimated that 10 million of the 28 million hearing impaired individuals in this country have losses resulting from exposure to loud noises. Most of these losses are entirely preventable!)

11) the study of presbycusis (progressive hearing loss in the aged)

12) expansion of the Intramural program

13) continued development of a Clearinghouse (results of the latest studies funded by the NIDCD would be made available to the lay public, researchers, professionals, and organizations)

Of great importance is the establishment of the federally mandated National Multipurpose Research and Training Centers. These are designed to support basic and clinical research, research training, continuing education for health professionals, and dissemination of information to the general public.

This year, in accordance with Congressional directives, we are hoping to fund 3-4 Centers, but under the President's recommended FY'91 budget for NIDCD, we would barely be able to maintain the Centers, and there would be no room for the growth we so desperately need.

Another area that still needs attention is space. We have had good, positive negotiations with the NIH and, should we be able to occupy the spaces planned, it will be satisfactory. The Administrative Staff and the Director will be in consolidated space in Building 31; the Extramural Program will be located in the Executive Plaza South; the Intramural Clinical Researchers are getting additional space in Building 10 (Clinical Center); and the remainder of the Intramural Basic Researchers will be assigned 6,000-10,000 square feet of additional space.

Yes, our goals for the Institute are high in accordance with the directives of this congressional body, but our researchers are excited and willing to tackle the responsibility, readily accepting the challenges that lie ahead.

Investigators now feel they can climb mountains which previously had been insurmountable. Dr. Josef Miller, of the Kresge Hearing Research Institute in Ann Arbor, MI, is one of our country's finest and most dedicated scientists. He reports that most of the researchers on his staff now come into their labs seven days a week, devoting at least 50% more time to their projects.

Because you have shown how much you care, our researchers are eager to continue the momentum you have inspired. This is not the time for NIDCD to plateau....our level of excellence must continue! How grateful we are to you for having given us a solid beginning! We hope that you understand more fully why we need to keep the funding at a level that would allow us not only to maintain our present programs, but to progress and evolve into a strong, effective Institute.

Therefore, Senator Harkin and Members of the Subcommittee, I respectfully request $165 million for NIDCD for FY'91 to adequately fund its research grants, training programs and centers.

Let us resolve now to put our energies and resources into the hope of the future and the promise of a more fulfilling and productive quality of life for our children, their children, and all future generations.

Justification for NIDCD Proposed Budget

$165 Million for FY'91

Budget Mechanism		Dollars in Thousands
Research Grants	**No.**	**Amount**
Research Projects:		
Noncompeting	326	$ 75,306
Competing	193	45,969
Subtotal	519	121,275
Research Centers	14	18,315
Other Research	52	4,950
Total Research Grants		144,540
Training Programs		
Individual Awards	40	1,155
Institutional Awards	72	2,800
Total Training	112	3,955
Research and Development Contracts	7	3,970
Intramural Research		6,270
Research Management and Support		6,265
TOTAL		$ 165,000

FY'90 Appropriations:	$ 117,583
FY'91 Projected:	$ 165,000

- Will allow support of 326 noncompeting grants at 100% of recommended costs instead of current policy to be able to fund only 90% of each grant.

- Will allow support of 193 new and competing grants at 100% of recommended costs. Will target studies in molecular biology and molecular genetics of hearing and other communication processes.

In 1989, the first gene for a hereditary cause of deafness (Ushers Syndrome, Type II) was identified and located by investigators at Boys Town National Institute (Omaha, NE). These findings substantiate that the methodology is now in place to vigorously pursue genetic causes of hearing impairment and deafness.

Additional studies would be able to capitalize on identification of the afferent and efferent transmitters from the inner ear (cochlea) to and from the brain. Any ability to use drugs in the treatment of problems such as tinnitus and Meniere's disease is dependent upon knowing the responsible neurotransmitters.

- Will allow initiation of 10 "mentor awards." These were designed and recommended by a group of consultants for improving the research training capabilities of the Institute. In brief, one postdoctural fellow would be assigned to a mentor for a minimum of two years to obtain "hands-on" laboratory experience. The mentor will be a current holder of a regular research project grant and will request a supplement to the grant to pay the salary of the fellow. Successful trainees have testified that their mentors were the most influential factor in their choice of a career in communications disorders research.

- Will allow the award of two additional Multi-Purpose Research and Training Centers outlined in the authorizing bill (P.L. 100-553). Emphasis will be placed on requesting applications addressing tinnitus and stuttering; two very difficult disorders which require interdisciplinary approaches to determine their diagnosis, treatment and prevention.

- Will allow the initiation of a program to award 15 small grants to support research of accomplished investigators who are using new techniques for studying communication disorders. This is considered particularly important for molecular biology and molecular genetics where a firm foundation in the science of the sensory or speech systems will be the prerequisite and, when acquisition of new technologies has been accomplished, these small grants will be used for feasibility studies for larger endeavors.

- Training funds will allow the development of one-to-two week intensive seminars for 10 predoctoral students to have laboratory experiences in such disciplines as cellular and molecular biology, neurolinguistics, computer modeling, acoustic measures of voice, and genetics. Seminars will be conducted by experienced NIDCD-supported investigators. Program will serve as a means of recruiting interested and talented individuals to research in the communication sciences and disorders.

- Training funds will allow postdoctoral basic and clinical science trainees to receive three years of supervised and research training. Trans-NIH data show that candidates with more than two years of training are more successful in becoming independent investigators.

- Will allow a research and development contract to establish the incidence, prevalence and risk factors for "specific language impairment." Currently, there are no existing incidence data on communication disorders on a national level and this contract will be the first of a number to describe the disorders within the NIDCD mission.

- Intramural research will be able to start a vestiblar unit in the Clinical Center to evaluate the balance-impaired adult and child, and conduct research for the development of new diagnostic methods and procedures.

Ms. Fox. Thank you. May I please introduce a dear, little friend, Rachel Dubin. This is her third year of testifying with us, and Rachel has just become 13 in October and had her bat mitzvah in Baltimore, where she not only read her portion, but she sang it. I would like to introduce you to Rachel Dubin who is a student at the Park School in Baltimore. She is in the eighth grade.

Senator Specter. It is nice to have you here, Rachel. Since the yellow light has not turned to red, would you care to add a comment or two?

STATEMENT OF RACHEL DUBIN

Ms. Dubin. Yes; good morning, Senator Specter and members of the subcommittee. This year I became a teenager. Every eighth grader at my school is required to give a speech to the entire faculty and middle school. I worried whether people would understand me, and worked very hard with my speech teacher to be articulate. The result was that I felt a tremendous sense of accomplishment, and even a seventh grader told me she could understand every word I said.

If you have teenagers, you know that one of the things we like to do is talk on the phone for hours. I can't do that. My parents bought me an extra TDD, which is a device for talking on the phone by typewriter so that I could loan the phone to friends and talk to them. However, it takes a long time to type messages and a lot of kids don't have the time or patience to do this.

Most people take watching television for granted. There is only one local station in Baltimore, WBAL, which has captioning three times a day for part of the local news. So, weather and sports segments are not captioned, so I'm without them.

I was not diagnosed as profoundly hearing-impaired until I was 3½ years old. Today, many hospitals test babies at birth for hearing loss and fit them with hearing aids almost immediately. Since this is the most crucial learning period for speech and language development, think how babies would benefit if this were available nationwide. The new institute can help us in many ways. Wouldn't it be great if someone could develop an earmold that wouldn't whistle, if damaged hair cells and neural tissue could be regenerated, if vaccines could be found for viruses that cause hearing loss, if hearing aids, listening devices, and other assistive devices could be improved. Hearing-impaired people can do anything, but we need a lot of help from our friends, and we consider this subcommittee to be our friend.

Thank you, Senator Specter and members of the subcommittee for allowing me to speak today.

Senator SPECTER. Thank you very much, Ms. Rachel Dubin, and you may be assured that we are your friends. Thank you, Gerry.

STATEMENT OF DIANA WOODRUFF-PAK, PH.D., AMERICAN PSYCHOLOGICAL ASSOCIATION

Senator SPECTER. I would like next to call on Dr. Diana Woodruff-Pak, division 20, adult development and aging. Thank you for joining us. We note your work with Temple University and it is a pleasure to have someone here from that distinguished institution.

Ms. WOODRUFF-PAK. Thank you. I am very happy to be here from the great city of Philadelphia. Senator Specter and other distinguished witnesses and guests, we appreciate very much the opportunity to testify here today.

The division of adult development and aging, which is called division 20 of the American Psychological Association, is a group of 1,300 Ph.D. psychologists working with academic research and clinical settings. A number of our members are grantees of the National Institutes of Health and also ADAMHA, so we are well placed to make suggestions to your subcommittee about scientific funding and funding for scientific research.

There are three major topics that I want to address today, the need for additional funds for basic research, the need to encourage and retain additional NIH and ADAMHA trainees, and the special need for additional funding of behavioral research at NIH. In my written testimony, I have had an opportunity to document more clearly the rationale for the additional appropriations we are requesting. Here in this testimony, I have time for only one quick example.

NIH research has advanced many frontiers of science. In my particular area of interest, behavioral neuroscience, we are on the verge of discovering some of the basic secrets about the neurobiology of learning and memory. We have mapped several of the learning and memory circuits in the brain and we are examining on a fundamental level what memory is. We are also exploring chemicals that might improve memory. The implications are very clear for normal aging, as well as for memory loss in Alzheimer's disease and in other dementing disorders.

The level of funding that you appropriate to the National Institute on Aging will affect how rapidly breakthroughs in memory occur. The breakthroughs will occur. The question is when, how soon they will occur. Will there be memory drugs for our generation, the generation who are adults now? Will there be memory drugs for our children's generation, or will we have to wait for our grandchildren to experience the benefits of such research?

The rate of our progress to maximize behavior in old age in general, depends largely on the level at which we fund research on aging now. An increase of $5 million, specifically targeted for behavioral and cognitive research over the proposed 1991 NIA budget, will accelerate progress in this important memory research. To accelerate the overall rate of scientific advance, to save billions for care and treatment, and to maximize the quality of life and alleviate suffering in the elderly, I strongly urge you to double the number of funded, new NIA grants for a total of $39 million.

Currently, only 17 percent of the proposals are funded. More than one-half of those, more than double of those number of proposals are very outstanding and merit funding, but the funds are simply not there. To train more behavioral, social scientists, we recommend an increase for funding of training at a level of $1.2 million increase. We particularly need more postdoctoral training for behavioral and social scientists. Finally, for special, social, and behavioral research programs at NIA, we recommend an addition of $24 million for their long term, training appropriation, $20 million for the health and behavior program, and $6 million for their work and retirement program. The resulting $95.2 million increase in 1991 funding for the National Institute on Aging, would provide a total appropriation of $344.2 million for this most important institute, but more importantly, it would provide an immeasurable future potential benefit for our aging society.

Thank you.

PREPARED STATEMENT

Senator SPECTER. Thank you very much for that testimony, Dr. Woodruff-Pak, and we will very carefully consider it. I would like now to turn to the testimony of Dr. Dominick Purpura for the Society of Neuroscience.

Your full statement will be made a part of the record.

[The statement follows:]

STATEMENT OF DIANA WOODRUFF-PAK

Mr. Chairman, Senators, and other distinguished witnesses and guests, we appreciate very much the opportunity to testify here today as public witnesses. The Division of Adult Development and Aging (Division 20) is a group of 1,300 psychologists with Ph.D. degrees working in academic, research, and clinical settings. Our members have a large range of interests in behavioral aging--from neurobiological basic aspects to social factors to clinical applications. A number of our members are grantees of the National Institutes of Health and ADAMHA, so we are well placed to offer suggestions about maximizing potential in old age and to suggest spending priorities to this Subcommittee based on our scientific experience.

There are three topics we want to address today: The need for additional funds for basic research; the need to encourage and retain additional NIH and ADAMHA trainees; and the special need for additional support by the Congress for behavioral research on aging.

One of our distinguished Division 20 members, Dr. M. Powell Lawton, Director of Research at the Philadelphia Geriatric Center pointed out that the mission of the National Institute on Aging is unique in being focused on a state through which most Americans will pass. One might say that aging gained official NIH recognition in 1974 when the NIA was founded. During the 16 years since that time, America has in turn recognized the last one-third of life both as a time with benefit to society at large and a time to be enjoyed by people of that age. The NIA led the way in stimulating research designed to improve the physical, psychological, and social health and functioning of older people. However, the rate of increase in funding for NIA has not kept pace with the growth of aging as a national phenomenon.

Members of Division 20 agree with the Pepper Commission's recent call for a $1 billion total commitment to research on the conditions of aging. Currently, only about 6% of NIH research funds are spent on aging. NIA's 1991 budget request is $248.9 million. Yet an estimated $215 billion will be spent in 1990 on treatment of Americans over age 65. We are spending one-thousandth of the dollars on research that we are spending on care and treatment. An additional investment of research dollars is essential for many reasons.

For decades gerontologists have noted that the aged are the most rapidly growing segment of our society. Since 1980 the older population has increased by over 6 million people. Life expectancy continues to rise, and 6,000 Americans turn 65 every day. The oldest-old, those over the age of 85 whose health and long term care costs are greatest, are increasing at the fastest rate. As the post-World War II baby boom generation ages, America's productivity will become increasingly dependent on the contributions made by the aged. We must be prepared to utilize better the talents of older adults as well as prepare to take care of them efficiently and effectively. Research is the most important means we have to make such preparations.

While the proposed 1991 budget request for the NIA will maintain funding at previous levels, it really represents a continued decline in new research project grants at NIA. In 1988 there were 214 new and competing research grants awarded, but 194 in 1989, 156 in 1990, and 153 projected for 1991. Between 1988 and 1990 there has been a 30 percent drop in the number of new competing research grants awarded by NIA, and the 1991 budget extends this plummeting trend. This trend is directly contrary to the pronounced increases in excellent applications, as increasing numbers of competent investigators have become concerned with aging. All this has a major, negative impact on research, creating a backlog of many excellent, unfunded research projects.

This backlog is most discouraging. The researcher's incentive to submit research grants on aging is dying. The odds are becoming so formidable that talented and well trained investigators give up altogether. Even for those of us who have been funded many times, it is daunting to contemplate the large time investment it takes to design and submit a research proposal when so few awards are available. Junior colleagues may be even more discouraged. Last year the American Psychological Association commissioned a study from the Rand Corporation which reported that there had been a striking decrease in the proportion of awards to researchers under the age of 35. In the past decade we have watched funding for research decline to the point where we have to have almost a perfect peer review score to be funded. Even when we get consensus on grants and receive very high priority scores, the odds for funding are against us. Not only do present funding levels prevent many highly meritorious grants from being funded, but these funding levels prevent untold hundreds of proposals from ever being conceived, written, or submitted. This is an immeasurable cost to scientific creativity in the United States.

Aging is one of the most complex of all scientific problems. Its secrets will not be yielded up in a short time. In 20 years the first wave of the post-World War II baby boom generation will start hitting age 65. We have begun to feel the impact now; yet we are reducing the number of federally funded research awards on aging. To begin to have answers on important issues of aging in five years, we need to initiate more research in 1991. NIA currently is funding only 17% of its approved research grants. More than twice that number of approved proposals could be funded without a decline in the quality of NIA-supported research. Thus, at a minimum, the number of new research awards should be doubled. An additional $39 million added to the 1991 NIA appropriation would achieve that goal.

Just as serious as the decline in the number of research awards is the decline in the number of funded trainees. We applaud Congress' action to establish the Claude Pepper Geriatric Research and Training Centers program, but we are still concerned that too few young researchers are choosing aging research as a career. Furthermore, we feel that the emphasis should be more broadly on training in gerontology, the multidisciplinary scientific study of normal aging, as well as on geriatrics, the medical study of disease in old age. A vast majority of older adults are healthy, and an increased number of scientists need to be trained to help older adults to maintain their health, functioning, and independence. We also need to examine older adults' potential for further contributions to our society. To deal with these issues, funding for pre-and post-doctoral training in behavioral and social issues on aging is particularly important, and should be increased in the 1991 appropriation by $1.2 million.

As psychologists, we are particularly interested in emphasizing the significance of behavioral research on aging. This Subcommittee last year instructed NIH to increase spending for health and behavior research, which has hit a plateau of only 3% of the NIH budget. We appreciate that vote of confidence and urge you to maintain the pressure to fund more health related behavioral research. In addition, behavioral research holds immense promise for understanding and affecting processes of aging. The scope of research on behavioral aging is broad, and certainly, in this short testimony, only a few highlights of behavioral research on aging can be presented to alert you to the potential for beneficial impact on an aging society.

Two very important points about behavioral research on aging are: gerontologists aim to maximize the quality of life; and behavioral research often provides means to reduce costs for care of the elderly. For example, the current annual cost of long term care services is estimated to exceed $50 billion, with an estimated $20 billion consisting of out-of-pocket payments by individuals and their families. In the 1990s and beyond, this staggering cost is expected to increase as the population ages. NIA-supported research on long term care aims to lay the knowledge base for legislative, regulatory, professional, and personal interventions to reduce the needs for long term care and institutionalization. Results from this research are also likely to improve the quality of life for older people needing long term care and diminish burdens on families. An increase of $24 million to the 1991 NIA appropriation should be made to meet the Institute's program for Behavioral and Social Research on Long Term Care.

Maintaining health can affect whether an aging individual maintains independence and avoids institutionalization. The 1979 Surgeon General's Report on Healthy People documented the importance of health habits and life-style factors for morbidity and mortality. An understanding of the pathways linking health and behavior and the interacting influences of age and other bio-social factors is important for improving the health and quality of life of older adults. Developing and testing the effectiveness of psychosocial interventions for promoting health-enhancing behaviors and discouraging health impairing ones can lay the knowledge base to reduce the burdens and costs of care associated with illnesses and disabilities caused or exacerbated by social and behavioral factors. To fund the NIA program on Aging, Health and Behavior, $20 million must be added to the 1991 NIA budget.

The changing nature of the labor force in the United States, with its increasingly large older segment and declining younger segment, has tremendous implications for the future productivity and well being of our country and its older citizens. Research on ways to optimize performance in older adults, to motivate them to remain in the workforce when their talents are needed, and to facilitate adjustment to retirement and productive roles outside the work force may significantly affect the way the United States functions in a changing world economy. An additional $6 million should be added to NIA's 1991 budget to fund research on work, retirement, and health, including $1.5 million for the new Health and Retirement Survey.

NIH research support has advanced many frontiers of science. In my particular area of interest, behavioral neuroscience, we are on the verge of discovering basic secrets about the neurobiology of learning and memory. We have mapped several learning and memory circuits in the brain and are examining on a fundamental level what memory is. We are also exploring what chemicals can make memory better. The implications for aging are obvious. In normal aging we all experience searching for a name or a word and complain of more frequent memory lapses. Of course, in Alzheimer's Disease and other dementing illnesses, memory is the characteristic behavior that is lost. The level of funding that you appropriate for NIA will affect when breakthroughs in memory, both in healthy and afflicted older people, occur. This type of research, investigating how memory and other cognitive capacities change in older adults, is currently being supported by the NIA within its Neuroscience and Neuropsychology of Aging program, but funding for behavioral and cognitive research there is insufficient to support many of the excellent grants that have been submitted. Another $5 million is recommended so that we can begin to understand which memory changes are to be expected as people age and which are signs of dementing illnesses. Without a firmer grasp of the physiological and psychological bases of memory, it will be virtually impossible to cure memory problems. Breakthroughs will occur: funding levels will affect how rapidly they occur. The question is: will there be memory drugs available to your generation, Senators, to your children's generation, or to your grandchildren's generation? The rate of our progress to maximize productive behavior in old age depends to a great degree on the level at which we fund research on aging. To accelerate this rate of scientific advance, to save billions for care and treatment and to maximize the quality of life and alleviate suffering for the elderly, we strongly urge you to double the number of funded new and continuing NIA grants ($39 million), increase funding for behavioral science training ($1.2 million), and increase behavioral research support for NIA programs on long term care ($24 million), health and behavior ($20 million), and work and retirement ($6 million). The resulting $95.2 million increase in the 1991 funding appropriation of NIA would provide both a total appropriation of $344.2 million for this most important institute and an immeasurable potential future benefit for our aging society.

STATEMENT OF DR. DOMINICK P. PURPURA, CHAIRMAN, NATIONAL COALITION FOR RESEARCH IN NEUROLOGICAL DISORDERS

Senator SPECTER. Next, Dr. Dominick Purpura of the National Coalition for Research in Neurological Disorders, we look forward to your testimony.

Dr. PURPURA. Thank you, Senator Specter.

Mr. Chairman, I am Dr. Purpura and I represent the 14,000 members of the Society for Neuroscience and the 50 voluntary agencies comprising the National Coalition for Research in Neurological Disorders. Neuroscientists have probably accepted the mandate of Congress to undertake the most comprehensive study of the brain in human history during the next decade, the decade of the brain. In this, the inaugural year of the decade of the brain, it is especially important that neuroscientists pursue opportunities for understanding basic brain mechanisms in health and disease, opportunities made possible by revolutionary developments that now permit identification of genes and gene products that regulate the operations of nerve cells and contribute to disorders that lead to Alzheimer's disease, muscular dystrophy, epilepsy, and the major mental disorders.

Neuroscience is correctly viewed as the most rapidly growing branch of the natural sciences and perhaps the most important. For neuroscience is the quest for the Holy Grail of humankind, the understanding of how the brain works and produces mind. We stand at the threshold of a new era in the brain sciences in which even the most complex functions of the nervous systems such as vision, movement, cognition, memory, learning, and addictive behaviors will be understood in terms of the properties of nervous system organizations. With this information and the promise of new knowledge to come in the decade ahead, neuroscientists will fulfill their obligation to the Congress and the people of the United States in carrying out the mandate of the decade of the brain. But our collective willingness is not enough.

The Society for Neuroscience and the National Coalition for Research are deeply troubled by the sharp reduction in the number of new and competing grants awarded by the National Institute of Neurological Disorders and Stroke, the National Eye Institute, and the National Institutes of Mental Health, all of whom make major contributions to the national effort in brain research. Curtailments in training funds for young investigators are having an impact that may do irreparable harm to the future viability of our research effort, an effort that has led the world in innovation and discovery. For example, in the past few years, American neuroscientists have identified the genes for Huntington's disease, Duchenne muscular dystrophy, and retinal tumors. They are in hot pursuit of the genetic mechanisms in Alzheimer's disease and the manic depressive disorders. We have pioneered new therapies in multiple sclerosis and Parkinson's disease and now neuroscientists have discovered ways of preventing the death of nerve cells following injury to the brain produced by stroke and head trauma. Many of these new insights have come from fundamental discoveries that have required innovative techniques and expert training that were not even dreamt of but a few years ago.

If the decade of the brain is to have any special meaning in the universe of human discourse, it behooves the Congress to provide funds equal to the task. In my statement, I have indicated the reasons why I think the Society for Neuroscience and the national coalition would enthusiastically, and do enthusiastically, endorse the professional judgment budgets of the following institutes: of the National Institute of Neurological Disorders and Stroke, we recommend $691 million or approximately $180 million more than the President's budget.

Senator SPECTER. How do you choose that figure?

Dr. PURPURA. It has been identified as the necessity to permit at least 400 more research grants and 150 training programs that we know currently exist and are now not necessarily being funded. And for the National Eye Institute, sir, we recommend $294 million and approximately $50 million more than the President's budget.

Senator SPECTER. How do you choose that figure?

Dr. PURPURA. That was also identified by the professional judgment opinion of the investigators working with the Institute director in relation to the known available talent, research training opportunities that are in the area of the National Eye Institute's purview.

Senator SPECTER. How much of the available talent would that grant the funds to?

Dr. PURPURA. Well, in our estimation——

Senator SPECTER. All of it, part of it?

Dr. PURPURA. The number of grants currently being funded by these institutes average about 20 percent of approved applications and that suggests when one looks at the cut-off points of those particular applications, at least another 10 or 15 percent are in the area of excellence for which it is very difficult to make distinctions. We believe that at least funding at the levels of 30 percent is a minimum and 35 percent of approved applications will, I think, stop this enormous drain on the potential for young investigators to want to enter the areas of biomedical science. We feel that's the crisis that we are facing by the shortfall in funds to meet the objectives of the institutes and of science and in the neuroscience programs.

If I might conclude with the statement, it is that neuroscientists view the decade of the brain which the Congress has committed us to as a prelude to the century of man in which humankind will be emancipated from the dread of disability and the stigma of dehumanization that attends disillusion of the human spirit and dementia. This is, in fact, special pleading for a very special cause. I thank you for your attention and for your very perceptive questions, sir.

PREPARED STATEMENT

Senator SPECTER. Thank you very much, Dr. Purpura. Mental health research received very considerable additional support last year. I wish we had time to discuss it in considerable detail. I am always at a loss to pick a figure. I would be interested if we had the time to hear more about how you make the suggestion and then I would, which we certainly don't have time for, have you sit in and hear all the other requests, so that you see some proportionality as to what we have to make allocations among.

Dr. PURPURA. Thank you very much.

Senator SPECTER. We will very carefully consider your testimony and your request.

[The statement follows:]

STATEMENTS OF DR. DOMINICK P. PURPURA

Mr. Chairman, my name is Dominick P. Purpura and I am pleased to appear before you today in my capacity as Chairman of the Citizens Budget Committee and member of the Board of Directors of the National Coalition for Research in Neurological Disorders, otherwise known as NCR. I am Dean of the Albert Einstein College of Medicine of Yeshiva University in New York.

Mr. Chairman, NCR is well known to this committee. I would like to advise the committee that this organization, representing more than 50 professional societies and voluntary health organizations that are interested in the expansion of neuroscience research, has been active in working toward the passage of the now well-known Congressional Joint Resolution declaring the 1990s as the Decade of the Brain. Our member voluntary health agencies represent persons suffering from some of the most debilitating and often chronic conditions affecting mankind. These neurological disorders affect the very young, persons in the prime of their lives, and the elderly. Our professional societies include those representing neuroscientists, neurosurgeons and neurologists who are dedicated to solving diseases of the brain, and central and peripheral nervous system.

The Decade of the Brain, passed by the Congress last year, has captured the imagination of many diverse organizations. At the federal level both the NINDS and the National Institute of mental Health are preparing implementation plans for the Decade. At the White House the Office of Science and Technology Policy is pulling all elements of the Federal government's research apparatus involved in the neurosciences together for creative planning.

In the private sector, many organizations are putting the Decade of the Brain logo on publications, stamps, and brochures. These same organizations are planning conferences, workshops and presentations based on the opportunities which lie ahead during this Decade. On the international level, we are seeing the neureoscientists in other countries take the Decade of the Brain to their own governments for endorsement. This is occurring in Europe, Japan and Africa.

Why is this response occurring? Let me asure you, Mr. Chairman, that the Decade of the Brain is far more than a slogan. The excitement arises because researchers see that promising developments are around the corner. For example, during the Decade, it is possible that we can learn how to prevent and reverse sensory loss that can occur during a stroke or a head or spinal cord injury. It is possible that we might be able to reverse brain damage by implanting new tissue into the living brain. It is likely that we will know much more about how the human nervous system and the immune system interact, allowing us to tackle such diseases as AIDS. And it is possible that we will develop methods to treat genetic disorders which cause neurological and mental disorders.

Mr. Chairman, the human brain is the final frontier of medical science. The frontier can be explored and mapped and cures developed during this Decade of the Brain. The worldwide community of brain researchers - including those active in mental health, education, cocaine addiction - implore Congress to make real the promise of our research.

Our message is very simple. There are several points I wish to make:

1. The National Institute of Neurological Disorders and Stroke (NINDS) is this country's leading research program devoted to funding research into more than 650 neurological disorders;

2. The scientific research momentum created in the field of brain research is at an all-time high;

3. The Administration's budget for NINDS allows funding of less than 20 per cent of new and competing approved grant applications, an all-time low.

It is NCR's desire that this committee appropriate $691 million to the NINDS for FY 1991. This amount of money is needed if we are to begin to realize maximum benefits from brain research.

Mr. Chairman and members of the committee, we seek your special consideration for this request.

Thank you for the opportunity to present this testimony before your committee.

Mr. Chairman, I am Dominick P. Purpura, M.D., Professor of Neuroscience and Dean of the Albert Einstein College of Medicine, Yeshiva University, New York. I come before the committee as a neuroscientist, Past-President of the Society for Neuroscience with a membership of 14,000 and currently President of the International Brain Research Organization. I am a member of the National Academy of Sciences and the Institute of Medicine. I am honored to represent the Society for Neuroscience and to endorse enthusiastically the professional judgement budgets of the National Institute of Neurological Disorders and Stroke ($691M), the National Eye Institute ($294M), and the National Institute of Mental Health ($750M).

Mr. Chairman, it is appropriate for the Society for Neuroscience to champion neuroscience research in the aforementioned institutes since these institutes assume the major responsibility for the support and conduct of basic research on the nervous system which includes the important function of vision and the control of eye movements. There is an additional reason. On July 25, 1989 the 101st Congress established Public Law 101-58, a "Joint Resolution to designate the decade beginning January 1, 1990 as the Decade of the Brain". Neuroscientists have accepted the resolution as a mandate for implementing the Congressional resolution that "the people of the Nation should be concerned with research into disorders and disabilities that affect the brain, and should recognize prevention and treatment of such disorders and disabilities as a health priority." We interpret this to mean that the unprecedented opportunities presented now for understanding the operations of the brain in health and disease must be specially highlighted because of their potential for alleviating, preventing and curing some of the most debilitating disorders of the human condition.

Brain is the organ of mind. It embodies the biological essence of what it is to be human. To the extent that its complex parts no longer serve to guide us with purpose, reason and judgement through the maze of human transactions that characterize us as Homo sapiens, Man of Wisdom, so too are we diminished. The "cost" in human suffering due to disorders of the brain, whether this be neurological, mental or visual is incalculable, as is the cost of these disorders to the Nation in lost productivity and management.

It has been noted recently that the United States has fallen behind other industrialized nations in its heavy industry, electronics and garment manufacturing. We can be justly proud of the continuing leadership of American scientists in the fields of biomedical and behavioral research. And no area of biological research has been more representative of these achievements than the field of neuroscience.

Through the leadership of the NINDS in neurological and neuromuscular research and research training, outstanding discoveries have emerged from U.S. laboratories including the intramural programs of the NINDS. One of the basic mysteries of the brain is how its 200 billion neurons and trillion non-neuronal cells are produced, differentiate and organize themselves into effective, functionally validated systems and maintain appropriate synaptic connections for over eight decades. Understanding the principles underlying these developmental processes in the brain, spinal cord and retina has resulted in the emergence of the field of developmental neurobiology whose aim is to understand how normal neuronal systems develop through the interplay of genetic and environmental (epigenetic) factors. At the same time we have learned how synaptic connections are affected by the expression of specific growth promoting factors under the control of genes that are "switched on" at the right time. Molecular genetics is now a constituent discipline of neuroscience. The fruits of its inquiries make it possible, through the detection of appropriate genetic markers, to identify chromosomal locations for the genes implicated in Huntington's Disease (HD), Duchenne muscular dystrophy (DMD), neurofibromatosis, and some of the major psychoses. From these discoveries it will soon be possible to identify the gene products that are deficient or poorly expressed. In the years ahead we will learn how these and other products contribute to neurological or mental disorders and blindness. The track record to date in accomplishing these goals is excellent, as evidenced by the remarkable progress being made by neuroscientists in studies of HD, Alzheimer's Disease and DMD. What was accomplished two decades ago in understanding the 'relatively simple' genetic defects in hemoglobin in several of the anemias, is now possible in the infinitely more complex disorders of the brain and its product, Mind. The job will simply take longer and require more effort ... and this translates into human resources and funds appropriate to this noble mission.

The American neuroscience community, now more than 15,000 strong and growing in intellectual and scientific strength almost daily, is now faced with the most stringent budget for growth and momentum maintenance in the past decade. New technologies for molecular biological and genetic research in nervous systems, mechanisms for imaging functioning systems involved in movement, vision, thinking and even in states of abnormal emotions, and the development of microphysiological and morphological techniques to study the dozens of neurotransmitter and synapse modulating agents from the stand point of their intimate kinetic details are the 'new age' instruments of the brain and visual sciences. It would be an egregious tragedy if we failed now to provide the support to our superbly trained neuroscientists to get on with the job ahead as mandated by Congress and the President.

The Decade of the Brain must be prelude to the Century of Man, emancipated from the dehumanizing disorders of Brain and Mind. The list of clues requiring hot pursuit now and in the years ahead would far exceed the required limits of this statement. Nonetheless, I would be remiss not to identify the most salient leads:

- A drug to slow the natural history of progression of Parkinson's disease
- The discovery of disease causing genes as well as genes controlling membrane ion-channel proteins, growth factors and transmitters
- Drugs to prevent hypoxic-ischemic damage to the brain by altering NMDA-receptor mediated systems involved in stroke-induced disorders
- New approaches to understanding neuronal excitation and inhibition in epilepsy
- Discoveries related to the molecular mechanisms of classical and associative learning
- Organization of neural systems in memory and cognition
- Basic mechanisms in schizophrenia and manic-depressive disorders
- Mechanisms of photoreception, organization of the visual systems, control of eye movements

It can be expected that these neuroscience insights will inform a wide range of neurological and psychiatric problems as well as mechanisms of vision and their disorders. The professional judgement budgets will permit neuroscientists to make great strides in the following areas:

- Clarification of mechanisms in the major anxiety and depressive disorders
- Understanding the role of basal ganglia and related systems transmitters and metabolic events in Parkinson's disease and other movement disorders
- Role of genetic factors in severe mental disorders and further pursuit of the HD, DMD and other genes and gene products
- Mechanisms of action of substances of abuse on neuronal organizations
- Basic mechanisms of cellular excitability in epilepsy

- Mechanisms of action of antianxiety drugs, anticonvulsants and the search for more effective agents
- Further analysis of the role of β-amyloid protein and its precursor as well as neurofilamentous changes in neurons, cholinergic systems and nerve and other growth factors in the genesis of Alzheimer's disease
- Analysis of AIDS dementia and the special effects of HIV infection of the brain in children and adults
- The capacity for regeneration and restitution of damaged neuronal elements in spinal cord trauma and head injury
- Studies in laboratory animals of nerve tissue transplantation in models of movement disorders, memory and learning deficiencies and circadian-rhythm disorders
- Studies of child and adolescent mental disorders
- Studies leading to early diagnosis of Alzheimer's disease, Huntington's disease and the major psychiatric disorders utilizing monoclonal antibody techniques, molecular genetics, brain imaging and epidemiological insights

The Society for Neuroscience submits that the foregoing opportunities for advances in neurological and psychiatric disorders can only be met by significant increases in the President's proposed budget for FY1991 for the NINDS, NIMH and NEI. It is for this reason that we endorse the professional judgement budgets of these institutes in the following amounts:

- National Institute for Neurological Disorders and Stroke ..... $ 691M
- National Institute of Mental Health ..... $ 750M
- National Eye Institute ..... $ 294M

In this, the inaugural year of the "Decade of the Brain", failure to provide the means to carry out the mandate to "focus needed government attention on research, treatment and rehabilitation in this area" can only be viewed as a retreat from a stated commitment to the People of the United States.

Senator SPECTER. I would like now to turn to Dr. James Lassiter, executive director of the National Dental Association.

Is Dr. Lassiter here?

STATEMENT OF J. ALFRED RIDER, PRESIDENT, CHILDREN'S BRAIN DISEASES FOUNDATION

ACCOMPANIED BY MICHAEL JOYCE

Senator SPECTER. I would like to turn then to Dr. J. Alfred Rider, president, Children's Brain Disease.

Dr. RIDER. I am Dr. J. Alfred Rider, president of Children's Brain Diseases Foundation and I have come here to speak on behalf of the disease called Batten disease. With me are Mr. Joyce, his wife, and two children who are afflicted. The two children have Batten disease. They are identical twins as you can see and so he is doubly affected by this disease. Every day a child is born with Batten disease; every day another child dies with Batten disease. Why does this occur? Primarily because very little money has been spent on specific research into the cause and treatment of Batten disease at the NIH. What is Batten disease? Batten disease is a neurological disorder affecting the brains of infants, children and adults. It occurs once in every 12,500 births; there are 440,000 carriers of this disorder in the United States. It is the most common neurogenetic storage disease in children. Although there are several types, the usual case is characterized by intellectual deterioration, visual loss, behavioral changes, the onset of progressively severe seizures and terminates in death. Patients may live, if that is the proper term, in this deteriorating state from 10 to 25 years, and in the case of my own son, Charles, he has survived 42 years, but now is in a completely helpless state. Although the Children's Brain Diseases Foundation has been very successful in getting Batten disease to be recognized worldwide, we have only been partially successful in advancing research to determine the cause of this disease.

Every day a child is born with Batten disease. Every day another child dies of Batten disease. The basic cause appears to be caused by a defective gene on chromosome 16. It is now proposed to isolate the gene. This is a very labor intensive and expensive task. The process is facilitated by families organized to supply blood and tissues as sources of DNA for these studies. Carrier detection will be possible when the disease gene and product have been identified—as is now possible in cystic fibrosis. The recent announcement by the Institutional Biosafety Committee of the National Institutes of Health of the approval of a proposal to treat children with a severe genetic disease by inserting new genes into their blood cells, makes this research all the more germane.

However, our foundation is extremely disappointed to find that in spite of the last year's wording in the appropriations bill about Batten disease, the committee continues to be aware that very little research has been funded; therefore, the committee directs the NINDS to more actively solicit, encourage, and provide guidance for applications for grants of quality for Batten disease research, or to otherwise take such steps that are necessary to assure that a vigorous research program is initiated. Nevertheless, very little research has been funded. In the last year, apparently, one grant for $100,000 to study a similar disease in New Zealand sheep was funded. It was estimated that two other grants were partially related to Batten disease. To be generous, a total of $425,000 was funded for the entire area. This is simply not enough—it is less than 0.1 percent of the NINDS budget—only a minuscule amount. Thus, we recommend the following wording:

> The committee learned that, in spite of former recommendations requesting research on Batten disease, little research has been funded. Therefore, it mandates that $2 million be specifically set aside in the budget by the NINDS for specific research on Batten disease for fiscal year 1990-91.

I think we have delayed long enough and, therefore, urge you to take this very appropriate action. There appear from 13 years of bitter experience in trying to encourage the National Institutes of Health to fund research specifically for Batten disease, that the only way to get them to fund such research is for your committee to put in its report that they are directed to set aside $2 million to be specifically for Batten disease research. Bluntly speaking, the Institute is simply not funding grant requests for Batten disease research. If they don't think the grant applications are good enough, then let them write their protocols and contract for specific research they have done with AIDS research.

The amount requested is a small price to pay to solve a disease which is draining our national financial resources to the tune of approximately $250 million per year based on approximately 300 children born with Batten disease and at a treatment and maintenance cost of $50,000 per year for each year of life. This life time, in a vegetative state, can last 10 to 20 years.

The brilliant discovery of the location of the defective gene in Batten disease was achieved without NIH support. It is now time for NINDS to step in and aid these researchers—who cannot get funding through the peer review system—in helping them to finish the job with good old-fashioned dollars.

Thus, by a stroke of a pen, you will not only earn the enduring gratitude of the thousands of patients and their families but you will stop the horrible waste of money for nursing and medical care for these children. These requests for research funds should enable us to determine the cause of Batten disease. This will lead directly to prevention and treatment. The future is in your hands. We implore you to be creative in your funding this year and give the NIH a mandate.

I know that goes against your policy. You would like to give the money to the NINDS and let them do what they will. But I think in this case we have waited long enough and we are not getting specific money set aside to do research in this very important disease and we are on the threshold of success of identifying the gene. We have 49 investigators all over the world.

Senator **Specter**. Dr. Rider, I think we have your point. We have your full statement. I would like to spend just a moment to hear from the parents.

STATEMENT OF MICHAEL JOYCE

Mr. JOYCE. We would appreciate that, Senator. We've brought Ian and Joe, not to ask for your sympathy, but just to let you see firsthand the devastation of this disease.

Senator SPECTER. Would you identify yourself for the record, please?

Mr. JOYCE. I'm sorry. My name is Michael Joyce and I am the father of Ian and Joseph Joyce. We have four sons and the baby is 2 years old and today we don't know if the baby has Batten disease or not. We had never heard of this disease.

Senator SPECTER. How old is your other son?

Mr. JOYCE. The oldest is seven.

Senator SPECTER. And these young men are how old?

Mr. JOYCE. Five and one-half. Now at the age of 3½ they appeared to be absolutely perfectly normal children.

Senator SPECTER. We see them here wearing the helmets; would you tell us why they wear the helmets?

Mr. JOYCE. Yes, sir; over the last 1½ years, they have become totally blind and this is a unique disease, in that, they start out as normal children so they never know of any handicaps and the brain deterioration appears to not make them aware that they have any kind of inability so they are very unstable and they fall down.

Senator SPECTER. And they went blind at what age?

Mr. JOYCE. They went blind about the age of 4½.

Senator SPECTER. And what other physical disabilities are apt to follow the blindness?

Mr. JOYCE. Ataxia, severe seizures and then they come into a complete degenerative state. We hope that you will listen to our plea this year. I went before the congressional hearings last year with Dr. Sycotis on behalf of the Children's Brain Diseases Foundation and we got that wording. I have since gone to NIH, met with the Director of NINDS, met with several people and I am just appalled that nothing has been done. This disease has been known for about 150 years and the devastation on the families is atrocious. Next year, I would like to come back and thank you personally. But next year when I come back, Ian and Joe will be in wheelchairs. This disease does not have any form of treatment, any form of detection, we are at a complete loss. We are devastated.

Senator SPECTER. Well, I know it is not easy for you to appear here and we appreciate your bringing your boys in. It certainly tells us much more than mere words.

PREPARED STATEMENT

Mr. JOYCE. We appreciate any help you can give us.

Senator SPECTER. Would your wife care to add anything? Thank you. Thank you very much. We will give very careful consideration to what you have said to us.

[The statement follows:]

STATEMENT OF J. ALFRED RIDER

I am Doctor J. Alfred Rider, President of the Board of Trustees of the Children's Brain Diseases Foundation. It is a pleasure to testify again before the Senate Subcommittee on Labor, Health and Human Services, Education and Related Agencies Appropriations.

Every day a child is born with Batten disease. Every day another child dies with Batten disease. Why does this occur? Primarily, because very little money has been spent on specific research into the cause and treatment of Batten disease by the National Institutes of Health. What is Batten disease?

Batten disease is a neurological disorder affecting the brains of infants, children and adults. Batten disease occurs once in every 12,500 births. There are 440,000 carriers of this disorder in the United States. It is the most common neurogenetic storage disease in children. Although there are several types of Batten disease, the usual case is characterized by intellectual deterioration, visual loss, behavioral changes, the onset of progressively severe seizures and terminates in death. This irreversibly severe illness constitutes an enormous nursing and financial burden to families with afflicted children. Patients may live, if that is the proper term, in this deteriorating state from 10 to 25 years, and in the case of my son, Charles, he has survived 42 years, but now is in a completely helpless state. The changes which occur in the brain in these children are quite similar to many of the changes which occur in the aging person. Thus, effective treatment for Batten disease may also allow us to alter the aging process of senility in all humans.

Although, the Children's Brain Diseases Foundation has been very successful in getting Batten disease to be recognized world wide, we have only been partially successful in advancing research to determine the cause of this disease.

Every day a child is born with Batten disease. Every day another child dies of Batten disease.

The basic cause of the disease appears to be caused by a defective gene on chromosome 16. It is now proposed to isolate the gene. This is a very labor intensive and expensive task. This process is facilitated by families organized to supply blood and tissues as sources of DNA for these studies. It is necessary to systematically survey a region of the chromosome containing millions of base pairs of DNA in which there may be hundreds of genes. These studies may provide a new means of pre-natal and pre-clinical diagnosis. Carrier detection will be possible when the disease gene and product have been identified (as is now possible in cystic fibrosis). If research support is available, the next step would be to identify the enzymatic defect. The recent announcement by the Institutional Biosafety Committee of the National Institutes of Health of the approval of a proposal to treat children with a severe genetic disease by inserting new genes into their blood cells, makes this research all the more germane.

However, our Foundation was extremely disappointed to find that in spite of the following wording in the House of Representatives, Departments of Labor, Health and Human Services, and Education, and Related Agencies Appropriation Bill, 1990 to wit:

> "Batten's disease--The Committee continues to be aware that very little research has been funded for Batten's disease. Therefore, the Committee directs the NINDS to more actively solicit, encourage, and provide guidance for applications for grants of quality for Batten's disease research, or to otherwise take such steps as are necessary to assure that a vigorous research program is initiated"

very little research has been funded for Batten disease and in fact, the research that has been funded has been part of over-all grants which included many other diseases. Also included is one grant of $100,000 to study a similar disease in New Zealand sheep. It is estimated that two other grants were partially related to Batten disease. To be generous, a total of $425,000 was funded for the entire area of Batten disease research. This is simply not enough--less than .1 percent of the NINDS budget--only a miniscule amount. There are still no specific grants to determine the cause and treatment of Batten disease. It is time we break with tradition and give the National Institute of Neurological Disorder and Stroke a specific direction with respect to Batten disease research. Thus, we recommend the following wording:

> "The Committee learned that, in spite of former recommendations requesting research on Batten disease, little research has been funded. Therefore, it mandates that $2,000,000 be specifically set aside in the budget by the NINDS for specific research on Batten disease for fiscal year 1990-91."

I think we have delayed long enough and therefore urge you to take this very appropriate action. There are over forty nine principal investigators from major universities, medical centers and institutes throughout the world interested in various phases of research pertaining to Batten disease. (See Addendums 1 and 2.)

It would appear from 13 years of bitter experience in trying to encourge the National Institutes of Health, NINDS, to fund research specifically for Batten disease, that the only way to get the NINDS to fund such research is for your Committee to put in its report that the National Institute of Neurological Disorder and Stroke is directed to set aside two million dollars to be used specifically for Batten disease research for fiscal year 1991. Bluntly speaking, the Institute is simply not funding grant requests for Batten disease research. If they don't think the grant applications are good enough, then let them write the protocols and contract for specific research as they have done with AIDS research.

The amount requested is a small price to pay to solve a disease which is draining our national finanical resources to the tune of approximately 250 million dollars per year based on approximately 300 children born with Batten disease and at a treatment and maintenance cost of $50,000 per year for each year of life. This life time, in a vegetative state, can last 10 to 40 years.

The brilliant discovery of the location of the defective gene in Batten disease was achieved without NIH support. It is now time for NINDS to step in and aid these researchers (who cannot get funding through the peer review system) in helping them to finish the job with good old-fashioned American dollars.

Again, every day a child is born with Batten disease; every day another child dies of Batten disease. With proper funding directed toward Batten's, this terrible waste can be stopped.

Thus, by a stroke of a pen, you will not only earn the enduring gratitude of the thousands of patients and their families but you will stop the horrible waste of money for nursing and medical care for these children. These requested research funds should enable us to determine the cause of Batten disease. This will lead directly to prevention and treatment. The future is in your hands. We implore you to be creative in your funding this year and give the NIH a mandate!

Addendum 1

Major Research on Batten disease Supported by Children's Brain Diseases Foundation

1. Bennett, M. J., The Children's Hospital Foundation, Philadelphia, Pennsylvania
   Characterization of the dyslipoproteinemia in neuronal ceriod-lipofuscinosis (NCL, Batten disease).
2. Dawson, Glyn, The University of Chicago, Chicago, Illinois
   Research into the biochemical basis of Batten disease.
3. Dratz, Edward, Montana State University, Bozeman, Montana
   Multifaceted approach to understanding the molecular defects in different forms of Batten disease.
4. Gardiner, R. M., University of Oxford, England
   Batten disease (Spielmeyer-Sjogren disease) and haptoglobins (HP): indication of linkage and assignment to chromosone 16 and isolation of the specific gene defect.
5. Katz, Martin L., University of Missouri School of Medicine, Columbia, Missouri
   An analysis of storage protein in hereditary ceriod lipofuscinosis (Batten disease).

6. Pullarkat, Raju K., Institute for Basic Research in Devlopmental Disorders, Staten Island, New York
Heterogeneity in ceroid-lipofuscinoses; Biochemical studies on ceroid-lipofuscinoses and Taurine availability in neurogenetic retinopathies.

7. Siakotos, A. N., Indiana University, Indianapolis, Indiana
The role of 4 hydroxynonenal in the pathogenesis of Batten disease.

8. Van Kuijk, Frederik J.G.M., Montana State University, Bozeman, Montana
A new role for phospholipase A 2: protection of membranes from lipid peroxidation damage and its possible relationship to its treatment of Batten disease.

Addendum 2

Comprehensive List of Investigators Actively Involved in Batten disease Research

1. Doctor Donald Armstrong
Kuwait University, Faculty of Allied Health Sciences and Nursing
Relationships of Peroxidase to Batten's disease
Canine Retinal Degeneration: An Approach to Therapy
Peroxidase Deficiency and Peroxidase Regulating Enzyme
Peroxidase Activity in Human and Canine Ceroid-lipofuscinosis, with Special Emphasis on the Eye.

2. Doctor Robert J. Baumann
Department of Neurology
University of Kentucky and Section on Epidemiology OBE, Office of the Director, NINCDS, Bethesda, Maryland
Leukocyte Ultrastructure.

3. Doctor Michael J. Bennett
The Children's Hospital of Philadelphia, Philadelphia, PA
Charactrization of the dyslipoproteinemia in neuronal ceroid-lipofuscinosis (NCL, Batten disease).

4. Doctor Xandra O. Breakefield, E. Kennedy Shriver Center, Waltham, Massachusetts
Molecular genetics of inherited neurologic diseases.

5. Doctor Milton Brightman
Lab. of Neuropathology and Neuroanatomical Sciences, NINCS & National Institutes of Public Health/Department of Health and Human Services
Transport of Horseradish Peroxidase Across Blood Brain Barrier.

6. Doctor S. Carpenter
Montreal, Canada
Biopsy Diagnosis in the Varieties of Ceroid-lipofuscinosis--Criteria and Pitfalls.

7. Doctor Glyn Dawson
Associate Professor, Departments of Pediatrics & Biochemistry, The University of Chicago, Chicago, Illinois
Pre-Natal Diagnosis and Enzyme Replacement Therapy.
Approaches to the Detection of Neuronal Ceroid lipofuscinosis in Cultured Skin Fibroblasts.
Abnormal Cathepsin Activity in Batten's disease.
Research into biochemical basis of Batten disease.

8. Doctor T. L. Dormandy
Whittington Hospital, London
Free Radicals and Lipopigments.

9. Doctor Edward Dratz
Department of Chemistry, Montana State University, Bozeman, MT
Measurement of Fluorescent Lipopigment, Peroxidized Fatty Acids, Vitamin E, Effects of Antioxidants on Lipopigment Formation.
Multifaceted approach to understanding the molecular defects in different forms of Batten disease.

10. Dr. P. R. Dyken, Mobile, Alabama
Reconsideration of the Entity of Ceroid-lipofuscinosis (NCL). Is it a Disease or a Syndrome?

11. Doctors Graig E. Eldred and Martin L. Katz
University of Missouri-Columbia School of Medicine
Lipofuscinogenesis in the Retinal Pigment Epithelium.

12. Dr. Y. Eto, Tokyo, Japan
A Clinical and Biochemical Exploration of Neuronal Ceroid-lipofuscinosis in Japanese Patients.

13. Doctor R. M. Gardiner
John Radcliffe Hospital, Oxford, England
Batten disease (Spielmeyer-Sjogren disease) and haptoglobins (HP): indication of linkage and assignment to chromosone 16 and isolation of the specific gene defect.

14. Doctor Paul Glees
University of Cambridge, Anatomy School, Cambridge
Electron Microscopic Studies on Neuronal Lipofuscin:Accumulation and Removal.
The Effects of Centrophenoxine in the Central Nervous System.

15. Doctors Hans H. Goebel and E. Dahme
Division of Neuropathology, University of Gottingen
The Ultrastructural Spectrum and Diversity of Lipopigments in the Neuronal Ceroid-lipofuscinosis.
Neuronal Ceroid-lipofuscinosis in the Dalmatian--a New Animal Model for Human Neuronal Ceroid-lipofuscinosis.

16. Doctor John M. C. Gutteridge
Division of Antibiotics, National Institute for Biological Standards and Control, Holly Hill, Hampstead, London
Fluorescent Products of Phospholipid Peroxidation: Formation and Inhibition on Model Systems.

17. Doctor James Gusella, Director of Neurogenetics Laboratory, Neurology Service Division, Massasachusetts General Hospital, Boston, Massachusetts

18. Doctor N. A. Hall, London, England
Accumulation of Dolichol-linked Oligosaccharides in Ceroid-lipofuscinosis.

19. Doctor Egill Hansen
Department of Opthalmology, Rikshopitalet, The National Hospital, University of Oslo, Norway
The Significance of Psychophysical and Electrophysical Methods in the Diagnosis of Juvenile Neuronal Ceroid-lipofuscinosis.

20. Doctor Ann Harden
Department of Clinical Neurophysiology, the Hospital for Sick Children, London
Neurophysiological Studies in Children with so-called Neuronal Ceroid-lipofuscinosis.

21. Doctor Denham Harman, The University of Nebraska Medical Center
Brain Lipid Composition.

22. Doctor K. U. Ingold
    Associate Director, National Research Council of Canada, Division of Chemistry
    Resistance to Oxidation and the Natural Antioxidant Levels in Membranes from Human Cells.

23. Doctor Gunde Egeskov Jensen
    The Laboratory of Biochemistry and Toxicology, the Institute of Biology and Chemistry, University of Roskilde, Denmark
    Glutathione Peroxidase Activity in Leucocytes, Erythrocytes and Serum from Juvenile Form of Neuronal Ceroid-lipofuscinosis.

24. Doctor R. D. Jolly
    Department of Veterinary Pathology and Public Health, Massey University, Palmerston North, New Zealand
    Ceroid-lipofuscinosis: The Ovine Model Studies on Mannosidosis and Ceroid-lipofuscinosis in Cattle, Sheep and Dogs.

25. Doctor Martin L. Katz, University of Missouri-Columbia, Columbia, Missouri
    An analysis of storage protein in hereditary ceroid-lipofuscinosis (Batten disease).

26. Doctor Edwin Kolodny
    Associate Director, Eunice Kennedy Shriver Center of Mental Retardation, Inc., Waltham, Massachusetts
    Pathogensis of the Neuronal Ceroid-lipofuscinosis.
    The Clinical Classification of Neuronal Ceroid-lipofuscinosis Subtypes.

27. Doctor Nils Koppang, Veterinaerinstuttet, Oslo, Norway
    Histochemical Evidence of Lipid Peroxidation in Canine Ceroid-lipofuscinosis.
    The English Setter with Ceroid-lipofuscinosis: A Suitable Model for the Juvenile Type of Ceroid-lipofuscinosis in Humans

28. Doctor P. M. MacLeod, Kingston, Canada
    The Prenatal Diagnosis of Jansky-Bielschowsky Disease During the Second Trimester.

29. Doctor Martin Maltempo
    Assistant Professor of Physics, University of Colorado Medical Center
    Monitoring of Peroxidase and Free Radicals in Canine Retinal Tissue Subject to a Degenerative Disease in which there is an Accumulation of Pathologic Lipopigments of the Ceroid Type: A Model for Batten's disease.

30. Doctor Jaime Miguel, NASA, Ames Research Center, Moffet Field, CA
    Analysis of Pigment Lipofuscin.

31. Doctor Sakkubai Naidu, Baltimore, MD
    Selenium Therapy in Ceroid-lipofuscinosis.

32. Doctor Erling Gronvold Olsen
    University Eye Department, Rikshospitalet, University of Oslo
    Fluorescein Angiography in Ceroid-lipofuscinosis.

33. Doctor D. Palmer, Palmerston North, New Zealand
    Chemical Analysis of Isolated Pigments from Ovine Ceroid-lipofuscinosis.

34. Doctor Vital Patel
    Assistant Professor of Pathology, Indiana University School of Medicine
    Antioxidant Treatment of Batten's Disease.

35. Doctor Alan K. Percy
    Associate Dean, Office of Research, Charles R. Drew Postgraduate Medical School, Los Angeles
    Salutory Effect of Selenium, Erythrocyte Glutathione Peroxidase.

36. Doctor Michel Philippart
Neuropsychiatric Institute, University of California, Los Angeles
Treatment of Batten's disease with Antioxidants.
Diagnosis and Treatment of Typical and Atypical Forms of Ceroid-lipofuscinosis.

37. Doctor Mark Poznansky
Associate Professor of Pathology, University of Alberta, Calgary, Canada
Enzyme Replacement and Enzyme Engineering.

38. Doctor Raju Pullarkat
New York State Institute for Basic Research in Mental Retardation, Staten Island, New York
Lipopigments in Aging and in Ceroid-lipofuscinosis.
Docosahexaenoic Acid Levels in Brains of Various Forms of ceroid-lipofuscinosis.
Oligosacccharyl Diphosphodolichols in Ceroid-lipofuscinosis.
Heterogeneity in ceroid-lipofuscinoses: Biochemical studies on ceroid-lipofuscinoses and Taurine availability in neurogenetic retinopathies.

39. Dr. P. Santauori, Helsinki, Finland
Fifteen Years Experience with Antioxidant Therapy in the Treatment of NCL Disorders.

40. Doctor Julius Schultz
Director, Pananicolaou Center Research Institute, Miami,Florida
Discovery and Characteristics of Leukocyte Peroxidase and the Purification and Administration to Animals.

41. Doctor Gunther Schwendemann
Division of Neuropathology, University Hospital Eppendorf, Hamburg
Diagnosis of Juvenile Ceroid-lipofuscinosis by Electron Microscopy of Lymphocytes and of Rectal, Skin and Sural Nerve Biopsy Tissue.

42. Doctor A. N. Siakotos, Professor of Pathology, Indiana University Medical Center, Indianapolis, Indiana
Development of a Reliable Blood Test for Batten's disease.
Recent Developments in the Isolation and Properties of Auto-Fluorescent Lipopigments.
The Neuronal Ceroid-lipofuscinosis: New Biochemical Findings.
The role of 4 hydroxynonenal in the pathogenesis of Batten disease.

43. Doctor P. E. Spoerri
Department of Histology and Neuroanatomy, University of Gottingen
Ultrastructural Age Changes in Neurons and Myocardium in Culture
The Effects of Centrophenoxine on Age Pigment.

44. Doctor S. K. Srivastava, Department of Human Biological Chemistry & Genetics, The University of Texas Medical Branch
Purification and Properties of Leukocyte Peroxidase
Biochemical Studies in Neuronal Ceroid-lipofuscinosis

45. Doctor Al Tappel, Division of Food, Science and Technology, University of California, Davis
Properties and Functions of Glutathione Peroxidase and Pentane Analysis of Lipid Peroxidation Damage to Quantitate Effects in Nutrition.

46. Doctor Frederik J.G.M. van Kuijk, Montana State University, Bozeman, Montana
A new role for phospholipase A 2: protection of membranes from lipid peroxidation damage and its possible relationship to its treatment of Batten disease.

47. Doctor T. Westermarck
Rinnekoti Institution for the Mentally Retarded, Espoo, Institute of Radiation Protection, Helsinki, Finland
Sodium Selenite Absorption and Losses in Spielmeyer-Sjogren Type of Neuronal Ceroid-lipofuscinosis (Batten's disease) Using Total Body Counting for 75 SE Detection
Studies on the Effects of Selenium Administration to Neuronal Ceroid-lipofuscinosis Patients with Special Refernce to Reduced Glutathione
Elemental Profiles of Blood Cells in NCL. Is Iron Involved in the Pathogenesis of NCL?

48. Doctor John R. Wherrett
Professor of Neurology Program, University of Toronto
Isolation of Fluorescent Material in the Juvenile Form of Batten's disease

49. Dr. H. M. Wisniewski
New York State Office of Mental Retardation and Developmental Disorders, Staten Island, NY
Lipofuscin in Aging.

50. Doctor Leon Wolfe
Hopital Neurologique de Montreal, Montreal Neurological Hospital
Characterization of the Accumulated Retinal Compounds in Batten's disease.
An Analysis of Urine Sediment in Subjects with Batten's disease.
New Findings on Abnornmalities of Dolichol and Dolichol Phosphates in Ceroid-lipofuscinoses and Relationships to Lysosomal Membrane Turnover.

51. Dr. C. E. Wright
New York State Office of Mental Retardation and Developmental Disorders, Staten Island, NY
Altered Taurine Transport in Ceroid-lipofuscinosis.

STATEMENT OF ALBERT H. OWENS, ON BEHALF OF THE NATIONAL COALITION FOR CANCER RESEARCH

Senator SPECTER. I would like to call now on Dr. Albert Owens, director of John Hopkins Oncology Center, National Coalition of Cancer Research.

Dr. OWENS. Thank you very much, Senator Specter, for the privilege of appearing. I represent as chairman of the coalition, 14 professional and lay organizations who are deeply committed to cancer research and broad biomedical research and I think to begin with I would like to thank you and your colleagues for the support that you supplied to these efforts over the years.

There are three things I would like to say, and maybe end with three questions since my formal statement will be in the record. One of the things that concerns me is that we seem to be overcome by the inevitability of cancer. How many times have you heard people say that we have spent millions of dollars on research and yet people are still dying of cancer. I can say that when I went to medical school, when you saw children with leukemia or people with Hodgkin's disease and testicular cancer that that was a death sentence, and we now can cure most of these people. And I think those of you who are in charge of the public trust will properly come back and say yes, but there are hundreds or thousands of people still dying of breast cancer or colon cancer or prostate cancer, and my retort to that, which I think is truthful, is that the gains that we have achieved show us the way to future gains. I am forced to be patient.

Senator **Specter**. You've carried on a good dialog with yourself, now I will ask a question. What is your prognosis as to how long—they asked me this morning if we've won the war on drugs—how long before we totally win the war on cancer by judgmental call?

Dr. **Owens**. I don't think I can accurately project that. Cancer has been stalking us for hundreds of thousands of years and I think we can cure cancer today. We do it all the time but it is going to be incremental, I feel, and I think I am optimistic about what we are learning about genetics. I think I am optimistic by what we learn about the transformation that under normal cells undergoing and becoming cancerous and that knowledge, I think, as it has in the past, is going to help us provide new treatments and prevention.

Senator **Specter**. How much money should we allocate to cancer? In fiscal year 1990, it's $1,634,294,000?

Dr. **Owens**. I think we are here to urge you to come as close as you possibly can to the bypass budget, that is $2.4 billion. The reason for that is that a number of people in the scientific community have thought that will help us get approved grants funded up to about 50 percent; will help us get full funding; will restore full funding to cancer centers which you know are going down, three or four a year; will help us with training, and my big concern is a lot of the gifted young people are turning away from the effort.

Senator **Specter**. $2.4 billion?

Dr. **Owens**. Yes, sir.

Senator **Specter**. Would you take $2 million less so we could give it to Batten disease?

Dr. **Owens**. I think we will—remember just two testimoneys ago that we heard about the retinoblastoma gene being discovered. One of the gentlemen that preceded me who is interested in neurologic diseases—just reminds you that the fundamental science that produced that was done in a cancer institute. I think there is a universality of supporting basic research that we shouldn't overlook. Would I take $2 million less, I think that's a judgment call. I just want to urge broad-based support because our chain is only as good as its weakest link.

PREPARED STATEMENT

Senator **Specter**. OK, thank you very much, Dr. Owens. It is a very, very important subject. We don't have any more important subjects than that and we will consider it very carefully.

Dr. **Owens**. I come every spring but for the last few years, just like the daffodils and the cherry blossoms, and I go away with a heavy heart because I think there is a lot of missed opportunities and we are losing ground. And I hope that the prospects for peace and whatever that we might see this year as a recommitment to our struggle against cancer, so I appreciate your interest very much.

[The statement follows:]

STATEMENT OF ALBERT H. OWENS

Mr. Chairman, Members of the subcommittee, thank you for the opportunity to present testimony today. My name is Albert Owens. I serve as Director of The Johns Hopkins Oncology Center. I also serve as a volunteer Chairman of the National Coalition for Cancer Research. My words represent the strong commitment of the 14 professional and lay organizations which constitute the Coalition to biomedical research in general, and to cancer research in particular.

May I begin my 3 minutes by expressing our profound gratitude for the support which you and your colleagues have consistently provided for cancer research. Those are deeply felt sentiments which we all share.

May I next invite your attention to 3 points and end with 3 questions.

1. There is a general public acceptance of the inevitability of cancer which caps strength from our resolve to accomplish its cure. How often do you hear such comments as "We've spent millions of dollars on research, yet we're losing the war against cancer" and, "When will we ever cure cancer?"

Mr. Chairman, you know that we cure cancer every day.

When I was a medical student, children with leukemia had a life expectancy of 3 months. Hodgkin's disease and testicular cancer were death sentences to thousands of young adults. Today, 95 percent of these children now survive without disease and are able to live healthy and productive lives. Three quarters of patients presenting with Hodgkin's disease are cured as are over 90 percent with testicular cancer. Those individuals will lead productive lives for another 15 to 30 years.

Yet, much remains to be done! While we can deal effectively with very limited disease, the common cancers of older ages, cancer of the breast, bowel, lung and prostate, are a major cause of suffering and death across the country. However, the cures that have been accomplished point the way to future gains.

Current research is yielding an abundance of new knowledge about the molecular events which underlie the transformation of normal cells into malignant cancers. Researchers are discovering the ways in which genes and environmental agents interact to cause the development of benign and malignant tumors. Highly skilled and dedicated scientists and physicians accomplish this research and translate its findings into clinical practice.

2. The United States has the finest and strongest biomedical establishment in the world. Some consider the combined strengths of its academic and industrial components awesome.

Permit me to underscore the fact that our country's position in the world of biomedicine is built on the productivity of research and the excellence of the people who complete it. the research "chain" is only as strong as its "weakest link."

Therefore, the members of the Coalition urge you to be as generous as possible in your appropriations for biomedical research. We hope you will be able to provide as a minimum $9.2 billion to the National Institutes of Health. This is a $1.4 billion increase over the 1991 President's Budget Request -- an increase which has been strongly endorsed by the Ad Hoc Group for Medical Research.

We also earnestly invite your support of the National Cancer Institute's By-Pass Budget which represents the scientific community's very thoughtful and responsible statement of needs and scientific opportunities. A $2.4 billion Cancer Institute budget would enable:

- Funding 50% of peer-approved grants
- Restoring funding of all grants to peer recommended levels
- Restoring full funding to Cancer Centers, and possible increasing their number by 5, from 56 to 61
- Significantly strengthening the clinical trials program
- Expanding and strengthening research training programs for young scientists and physicians

An appropriation of $2.4 billion will allow us to regain some of the ground we held when the National Cancer Act became law in 1971. An appropriation at this level will enable strengthening of all the links to our research data.

Equally important, it will encourage highly talented young scientists and physicians to commit their lives to cancer research and treatment. Unfortunately, many of the brightest and the best are now turning away.

3. Biotechnology is a vital element of our national economy. There is a great risk of losing our biomedical leadership position in the world.

The scientists who work in industry come from our colleges and universities. Many of the discoveries made in university laboratories are developed by industry into products and services of great commercial and societal value. A continued investment in biomedical research and research training of young scientists is necessary to maintaining our leadership position.

Gentlemen, please consider my 3 closing questions:

1. As director of the Johns Hopkins Cancer Center, it is my responsibility to obtain maximum value for every dollar spent. We need to purchase an electron microscope. We have examined all

models suited to our requirements. Our final choice is between the Japanese and the German model.

Why is there no American model in the competition?

2. In 1950, all of us would have been proud to acknowledge the American Automobile Industry as the finest in the world.

What will be said about the American biomedical enterprise in the year 2000?

Each spring, you permit several of us to appear before you to plead our causes. We come like the daffodils and cherry blossoms and perform our civic duties to the best of our abilities.

Over the last several year, we have left with heavy hearts. Our "heads" have understood the needs for strong defense forces and crushing burden of the national debt. Nonetheless, our "hearts" feel the losses and missed opportunities in cancer research that are vital to our Country's vigor, and to the 1,000,000 or more men, women and children who will be diagnosed as having cancer this year.

With the prospects for peace in the world so greatly improved, will this be the year of a renewed national commitments to the struggle against cancer?

Thank you for the privilege of appearing before you.

STATEMENT OF J.A. PISCOPO, TREASURER, AMERICAN NARCOLEPSY ASSOCIATION

Senator SPECTER. I call now Mr. J.A. Piscopo, American Narcolepsy Association.

Mr. PISCOPO. Thank you, Mr. Chairman. I am the treasurer and a director of the American Narcolepsy Association, which represents 4,000 persons afflicted with narcolepsy.

I have narcolepsy myself. It is a sleep disorder that is characterized by inappropriate daytime sleepiness. Narcolepsy is a lifelong illness, and there is no known cure. It is estimated that more than

200,000 Americans suffer from narcolepsy, making it more prevalent than muscular dystrophy or hemophilia.

Mr. Chairman, narcolepsy research is conducted through the National Institutes of Neurological Disorders and Stroke. Last year I told this subcommittee that for the prior 3 years, I had personally funded more narcolepsy research than the NINDS, a total of nearly 2 million dollars' worth. I testified that a much higher level of funding was needed for narcolepsy research within the National Institutes of Health.

We were very pleased with your subcommittee's response to our pleas last year. The final reports of both the House and Senate's Appropriations Committees reflected specific recommendations that greater resources be dedicated to narcolepsy research. The NIH reauthorization bill passed last year authorized the National Commission on Sleep Disorders Research.

Unfortunately, Mr. Chairman, there has been no apparent increase in either the efforts or in the funding for narcolepsy research by the National Institutes of Health. We urge you to adopt even more specific, stronger language into the appropriations reports this year. Not only must more funds be appropriated for narcolepsy research, but the funds must actually be spent by the National Institutes of Health.

There is a need for a separate and distinct program for narcolepsy research to be established. Such a program for narcolepsy should be responsible for directing and coordinating all narcolepsy and sleep-related research throughout the NIH. A specific person should be designated and given responsibility for the program.

This would promote greater individual accountability and public awareness, more initiative for narcolepsy research and also enhance the cooperation between the National Institutes of Health, the Congress and the private citizens in the United States who are concerned or afflicted with narcolepsy.

Mr. Chairman, I have been appointed as a member of the National Commission on Sleep Disorders Research. The commission will examine the steps needed to take place on the Federal level to more adequately deal with narcolepsy and other sleep disorders.

PREPARED STATEMENT

I hope that the subcommittee will seriously support the long-range plan developed by the commission and implement its recommendations.

Thank you again, Mr. Chairman, for your continued support for increased Federal funding of narcolepsy research.

Senator SPECTER. Thank you very much, Mr. Piscopo.

We appreciate your testimony. We understand the seriousness of the problem, and we will weigh it very carefully when we make our allocations.

Mr. PISCOPO. I thank you, sir.

[The statement follows:]

STATEMENT OF J.A. PISCOPO

Mr. Chairman and members of the Subcommittee, I am Joe Piscopo, the treasurer of the American Narcolepsy Association. ANA is an organization of about 4,000 members who have narcolepsy, a serious disorder that I will describe to you briefly.

If not for the controlled substance medication that I take daily, it is not likely that I would be able to appear before you today. Narcolepsy is a disorder that manifests itself in a number of ways:

One, narcolepsy renders a person unusually sleeply all of the time, no matter how much sleep the victim gets at night. A person with narcolepsy always feels like he or she has been awake for several days.

Two, a person with narcolepsy is likely to fall asleep during a conversation, while eating, or anytime. Needless to say this is embarrassing, but can also have serious implications in work settings and on the highway.

Three, cataplexy is a symptom of narcolepsy that paralyzes a person during an attack. During a cataplexy event a victim loses all muscle tone and becomes unable to move. Something as simple as being told a joke can spur a paralysing narcolepsy attack. Any other emotional peak can trigger cataplexy, such as sexual arousement.

Four, dreaming is especially unusual for narcolepsy victims. Vivid nightmares are frequent and many times a narcolepsy victim cannot distinguish between dreaming and reality. Younger victims have especially frightening and grewsome nightmares.

Mr. Chairman, I am an exception to the rule. Most victims of narcolepsy spend their lives moving from job to job after being fired because they are considered lazy. However, many narcolepsy victims are totally disabled and do not lead much of a life at all.

It is estimated that as many as 200,000 persons in the country have narcolepsy, many of whom are undiagnosed and untreated. Because it is a progressive disorder, many narcoleptics go undiagnosed for years, just assuming that they are always tired.

The National Institute on Neurological Disorders and Stroke has been the traditional NIH entity that provides funding for narcolepsy research. Despite urging from this subcommittee, the NINDS has not made a significant effort to provide more emphasis on narcolepsy research. Even though narcolepsy outpaces multiple sclerosis and epilepsy, very little is being done. The American Narcolepsy Association is waiting with much hope that the NINDS will follow through with the Committee's recommendations and sponsor an International Symposium on Narcolepsy Research, and increase their funding of investigation of this disorder.

Finally, Mr. Chairman, as you may know, I have been appointed as a member of the National Commission on Sleep Disorders Research. During the next year and a half, the Commission will examine the steps that need to take place on the federal level to more adequately deal with narcolepsy and other sleep disorders. I hope that this subcommittee will seriously consider the long range plan established by the Commission and implement its recommendations.

I would be pleased to respond to any questions you may have.

Senator **Specter**. We have been joined by Senator Bumpers now, to whom I will yield the gavel——

Senator **Bumpers**. You are so kind.

Senator **Specter** [continuing]. After one private word.

Senator **Bumpers** [presiding]. Let me say to the last witness that I am extremely sensitive to narcolepsy. I happen to live with a victim.

STATEMENT OF DAVID SATCHER, PRESIDENT, MEHARRY MEDICAL COLLEGE ON BEHALF OF THE ASSOCIATION OF MINORITY HEALTH PROFESSIONS SCHOOLS

Senator **Bumpers**. Our next witness is Dr. David Satcher, president, Meharry Medical College, for the Association of Minority Health Professionals.

Dr. Satcher, welcome, and please proceed.

Dr. **Satcher**. Thank you, Senator Bumpers. I am very pleased to have this opportunity to speak on behalf of the Association of Minority Health Professions Schools.

As you know, there are eight members of our association, including three schools of medicine, one school of dentistry, three schools of pharmacy, and one school of veterinary medicine. I will not name our schools since they are listed in my written presentation, but I will say that, according to a 1980 study, 40 percent of the Nation's black physicians, 40 percent of the Nation's black dentists, 50 percent of the Nation's black pharmacists, and 75 percent of the Nation's black veterinarians are graduates of our institutions.

I will also say, Senator Bumpers, that 3 years ago, a Mrs. Annie Wilson, who lived in Arkansas, passed and left her entire estate of $100,000 to Meharry Medical College because of the number of black physicians that she had known in Arkansas who had finished our institution. This was a lady who did not even have air-conditioning in her home but was very sensitive to the need to support these institutions.

In addition to the people who have been in practice in underserved communities, just a few days ago the National Institute of Allergy and Infectious Diseases announced the funding of an AIDS consortium center to combat AIDS among minorities, and this consortium center is funded to the AMHPS institutions.

We are here today because we would like to express our support for the proposed 1991 budget for the Department of Health and Human Services, as submitted by Secretary Sullivan. We feel that the funding level that has been proposed is reasonable and that it is responsive to the 1985 task force report pointing out the significant gap in the health status that exists in this country between blacks and whites, and the fact that every year more than 60,000 unnecessary deaths take place because of this gap.

So we strongly support the increase in funding that is recommended. We feel it is appropriate and that it is not excessive.

Our only concern, however, is that we be sensitive to the need to continue to fund the health professions, including family medicine, the area health education centers that have made such a difference in allowing students and residents while they are in training to get experiences in low-income and underserved communities such as Lee County, AR, and areas throughout Tennessee and Mississippi. So we want to just urge you to continue to support the health professions.

We are disappointed, however, in the budget for the Department of Education. We do not feel that it is consistent with President Bush's commitment to education. We are especially concerned about the proposed cuts in guaranteed student loans of $1.3 billion. We do not feel that that is justified.

PREPARED STATEMENT

We feel that, given the problems that we face in this country in terms of minorities in the penal system, that the efforts to get more minorities through higher education should be expedited at this time in our history. So we are urging you to continue to fund progress in higher education for minorities, especially in the health professions.

[The statement follows:]

STATEMENT OF DAVID SATCHER

Mr. Chairman and members of the Subcommittee, thank you for the opportunity to present the views of the Association of Minority Health Professions Schools.

Our Association is comprised of 8 historically black health professions schools, the Meharry Medical and Dental Colleges, in Nashville, TN; the Charles R. Drew University of Medicine and Science in Los Angeles, CA; the Morehouse School of Medicine in Atlanta, GA; the Florida A&M University College of Pharmacy in Tallahassee, FL; the Texas Southern University College of Pharmacy and Health Sciences in Houston, TX; the Xavier University of Louisiana College of Pharmacy in New Orleans, LA; and the Tuskegee University School of Veterinary Medicine in Tuskegee, AL. These institutions have trained 40% of the nation's Black physicians, 40% of the nation's Black dentists, 50% of the nation's Black pharmacists, and 75% of the nation's Black veterinarians. Most of these graduates are working in the nation's underserved rural and inner city communities. Mr. Chairman, we are very proud of the accomplishments of our institutions, especially given the significant challenges that we have overcome throughout our existence. Our schools are considered by many to be a national resource. Only recently has the federal commitment to supporting these institutions and the students who attend our schools become a significant issue.

For a long time our schools have struggled against terrific odds to survive. Now we wish to thrive. The support of your subcommittee in terms of federal resources for programs impacting our students and our institutions has had and will continue to have a significant impact.

HHS Budget Proposal

Mr. Chairman, the proposed budget for FY'91 for the Department of Health and Human Services is very thoughtful with respect to minority health initiatives. The requested levels of funding in the budget proposal for minority health initiatives, and for training minorities in the health professions is responsive to those recommendations made by the 1985 HHS Secretary's Task Force Report on Black and Minority Health. The recommended levels are neither excessive nor extravagant -- but a major step toward responsiveness to the problems outlined in the report. We feel very strongly that this type of commitment is appropriate and represents more than just rhetoric spewed by former budget proposals. In short, it begins to put its money where its mouth is.

We are concerned however, that there may be a growing sentiment to trade the support for current health professions programs for the minority health initiatives. A move like that would be totally inappropriate. The minority health initiative is a distinct and critical thrust that cannot replace support for traditional health professions training programs. Similarly, the thrust of the minority health initiative should not be watered down in the attempt to encompass the intent of those programs designed to assist a broader population. The specific needs and challenges facing this nation relative to minorities are quite clear.

Mr. Chairman, the HHS Secretary, Dr. Sullivan is to be commended for his leadership on the minority health initiative. Also, Congressman Stokes, a member of this subcommittee should be commended for his leadership on this current issue, and for his past support.

Education Department Budget

The FY'91 budget proposal for the Department of Education is disappointing. President Bush's commitment to education is certainly not reflected in the proposed cut in Guaranteed Student Loans by $1.3 billion. We believe that Guaranteed Student Loans need continued adequate support. It does not appear that there will be a dramatic drop in interest rates as is explained by their budget justification, so this continued support will be necessary.

Closer to home, the recommended level of support for Historically Black Colleges and Universities is still inadequate. Similar to the thrust at HHS in minority health, the Education Department should develop and put forward a comprehensive plan that will address the national problems that suppress educational opportunities for minorities. Academic preparedness, retention, role models, faculty, indebtedness, institutional support are all terms that represent problem areas for Blacks and other minorities in education, and for the schools that train these individuals. As pointed out in the American Council of Education's report One Third of a Nation, the preparation of minorities for the 21st century must be a national priority or the nation will suffer.

The programs that are targeted to HBCUs must be more adequately supported. For example, the Title III HBCU graduate institution program should be increased dramatically, so other similar institutions can participate. AMHPS supports including more, select institutions in this program, but with increased funding to accommodate their needs while not displacing the support for currently participating schools.

Specific Programs

Exceptional Need Scholarships, Disadvantaged Assistance, and Excellence in Minority Health.

Mr. Chairman, the Association of Minority Health Professions Schools is very pleased that the President's FY'91 budget proposal includes funding increases for each of these vital programs that support disadvantaged and minority health professions training, retention, recruitment and faculty. These programs represent a significant commitment by HHS to progressively deal with the shortage of health professionals in this country. We firmly believe, however that the other traditional health professions programs should be supported as well.

Research Centers in Minority Institutions, Minority Biomedical Research Service, Minority Access to Research Careers.

These critical initiatives all contribute to the ability of our institutions to develop a sound research infrastructure and attractive environment for scientific investigation. AMHPS supports the continuation and enhancement of these initiatives through increased funding and various BID co-support.

In an effort to make further progress in studying disorders that disproportionately impact Blacks and other minorities, the Association of Minority Health Professions Schools supports the establishment of a goal of providing 3% of total NIH funding to minority related research within 5 years and 5% in 10 years. Currently about 1% of NIH funds are provided for minority-related research.

Disease Control & Epidemiology

The Association of Minority Health Professions Schools has entered a cooperative agreement with the Centers for Disease Control to document, study and deal with those diseases that disproportionately affect minorities. AMHPS commends the CDC on this important development and recommends continued support.

Education Initiatives, Title III

The Association of Minority Health Professions Schools recommends that the Department of Education establish a comprehensive proposal similar to that of HHS in supporting the educational advancement of minorities in all professional disciplines. The severe underrepresentation of minorities in the health professions and health sciences and the poverty of minority faculty for graduate professional schools all demonstrate the urgency of these programmatic needs.

AMHPS commends the Congress for its continued support of Historically Black Colleges and Universities. The Title III, section 326 program supporting graduate institutions could be expanded to include more institutions, but a significant increase in funding should accompany this program change.

Mr. Chairman, thank you for the opportunity to discuss the views of the Association of Minority Health Professions Schools. And again, thank you for your outstanding support.

Senator **Bumpers**. Dr. Satcher, let me say first of all there used to be a young, good-looking, dynamic Governor in Arkansas who started the AHEC program, and it has been a resounding success.

Dr. **Satcher**. Yes; and we appreciate that.

Senator **Bumpers**. The National Health Service Corps, which I thought was one of the best programs we ever had in this country, has been almost decimated. You mentioned Lee County. There would be no health care——

Dr. **Satcher**. That is right.

Senator **Bumpers** [continuing]. In Lee County if it were not for that program.

Dr. **Satcher**. That is right.

Senator **Bumpers**. And I must give the President his due. As you know, President Reagan tried to zap the Health Service Corps program every year and just about got it done.

Dr. **Satcher**. That is exactly right.

Senator **Bumpers**. And to George Bush's credit, he has asked for, I believe, about or in excess of $55 million to reinstitute the program this year.

Dr. **Satcher**. That is right, $55 million.

Senator **Bumpers**. And I am hot for it. Now I have got Ted Kennedy on my hands. He wants to put all the doctors in inner cities. And, of course, I am worried about Lee County.

Dr. **Satcher**. That is right.

Senator **Bumpers**. Let me just ask you one question, Dr. Satcher. And incidentally, I knew Annie well.

$83.898 million, which you say is inadequate. Give me the figure you think is just about right, considering the budget constraints we are operating under.

Dr. **Satcher**. Let me say specifically that I was specifically speaking of the graduate programs in health professions, which are a little in excess of $11 million, and we are hoping that they will continue to grow.

The $83 million is the title III for all of the historical black colleges and institutions, not just the health professions schools. While we don't have a specific figure, we feel that what we should see in higher education is continued growth in those programs until we begin to resolve the problem of the underrepresentation of blacks and other minorities in the health professions.

Let me give you one example. Throughout the country, all institutions, the majority and minority institutions, are complaining about the shortage of minority faculty. In all of the medical schools in the country, only 2.7 percent of the faculties are minorities. That is blacks, Hispanics, Puerto Ricans all combined. These institutions have produced more than 40 percent of those faculty, and I think those programs need to be supported more aggressively as opposed to cutting back on them.

Senator **Bumpers**. Thank you very much, Dr. Satcher.

Dr. **Satcher**. Thank you.

STATEMENT OF ROGER N. ROSENBERG, PRESIDENT-ELECT, AMERICAN ACADEMY OF NEUROLOGY

Senator **Bumpers**. I am going to ask everybody else's indulgence because Dr. Rosenberg has to leave here by noon. So, Dr. Rosenberg, we will be delighted to hear from you at this point.

Dr. **Rosenberg**. Thank you very much, Senator Bumpers. I appreciate the opportunity.

Senator **Bumpers**. Welcome. We are glad to have you. Please proceed.

Dr. **Rosenberg**. Thank you, sir.

We have established national scientific priorities to build a supercollider linear accelerator for studying subatomic particles, and the genome project for sequencing human DNA. Both are laudable goals and have important consequences for our society.

Brain function and its diseases represent one of the remaining major frontiers before biomedical research. The time is ripe for our Nation to capitalize on this vast body of basic scientific data and apply it to brain diseases.

The Congress should establish a third national scientific priority for the next decade, in our view, a concerted program to decipher the major brain diseases.

I am Dr. Roger Rosenberg, and I am professor and chairman of the Department of Neurology at the University of Texas Southwestern Medical School in Dallas, and president-elect of the American Academy of Neurology, which represents 10,000 neurologists and neuroscientists across the United States and worldwide.

All practicing neurologists, Senator, are aware of the staggering number of our citizens who suffer from Alzheimer's disease, Parkinson's disease, stroke, multiple sclerosis, muscular dystrophy, neurogenetic diseases, epilepsy, motor neuron disease, and mental illness. In fact, more people are hospitalized in our country with brain diseases than all other major disease groups, including cardiovascular disease or cancer.

Our basic science colleagues have provided medical neuroscientists with a vast background of information that can be applied to brain diseases. A fourfold increase in the budget for the National Institute of Neurological Diseases and Stroke, NINDS, over the decade of the 1990's, the Decade of the Brain, will allow major new research initiatives to begin in each of these disease areas and fund up to 60 percent of scientifically approved research grants at institutions across the country.

Every institution pursuing comprehensive research in the neurosciences will benefit, and ultimately, our patients will benefit.

In my view, Senator, it is a national disgrace when, as a result of inadequate budgetary growth, less than 20 percent of approved neuroscientific grants for fiscal year 1989–90 will be funded by NINDS. Last year it was 34 percent of approved grants were funded, and the year before that, 40 percent. So, in 2 years, sir, we have taken a 50-percent reduction in the number of approved grants that have been funded. It is a disincentive to our brightest and best minds, who have established or who are contemplating a career in the neurosciences, to receive this news.

PREPARED STATEMENT

We as a Nation and a people can do much better. It is our recommendation, therefore, that a $200 million increase be applied to the NINDS budget to raise it for fiscal year 1991 to $690 million. At that level, at least 50 percent of approved scientific grants can be funded. An increase in 400 grants over this year can be funded, as we heard earlier from Dr. Purpura.

Thank you very much, Senator.

[The statement follows:]

STATEMENT OF ROGER N. ROSENBERG

In testimony before the subcommittee, National Institute of Neurological Diseases and Stroke Director, Dr. Murray Goldstein discussed "three successes and three failures" in recent neuroscience research. The success stories include a breakthrough in the treatment of Gaucher's disease, discovery of important drug therapy for Parkinson's disease, and clinical application of a drug that stops atrial fibrillation--which contributes to occurrence of strokes. Dr. Goldstein characterized our inability to solve the mystery of ALS (Lou Gehrig's disease), the increasing incidence of stroke, and the continuing challenges presented by head and spinal-cord injury, as areas in which we have failed.

As physicians and neuroscientists, the members of our organization would prefer to look upon the latter list as "areas of scientific opportunity", rather than as "failures". Congress designated the 1990s the "Decade of the Brain" in recognition of the importance of neuroscience research, and in the belief that past scientific advances will pave the way for even greater achievements. We wholeheartedly agree. We would like nothing more than to have today's so-called "failures" become the accomplishments of tomorrow. With a significant funding increase for brain research, we are confident that this expectation is realistic.

We come to the appropriations committees with a request to help make the "Decade of the Brain" more than just a commemorative resolution: Currently, the National Advisory Neurological Disorders and Stroke Council is preparing an implementation plan for the early years of the "Decade", which will represent a **national consensus** for the immediate future of brain research. In preparation for receipt of the plan by June, 1990, the appropriations committees should address now, in its fiscal year 1991 appropriations deliberations, the appropriate increase in resources which will be needed in order to make possible the specific research objectives associated with the "Decade of the Brain". We would like to recommend a substantial increase of $200 million for NINDS for FY 1991, bringing the institute's funding commitment to a level of approximately $690 million.

The current funding level at NINDS is not sufficient to support the expanded research objectives associated with the Decade of the Brain. In part due to a variety of mandated reductions, and the effect of the partial sequestration, the current fiscal year will see substantially fewer new and competing grants funded than in the previous fiscal year (approximately 421 grants compared to 493 in FY 89). It is projected that only 20% of competing research grants will be able to be funded, (a drop from 34% last year, and over 40% in fiscal years 87 and 88), with cuts averaging over 11 percent built-in. If grants were funded at peer-review recommended levels, only 12% of approved grant applications would receive funding in the current fiscal year.

The obvious impact of this funding shortfall on our ability to continue to support a sufficient amount of research in the neurosciences is coupled with the impact the situation has on our nation's ability to attract and maintain an adequate cadre of neuroscience researchers: As bright young people entering the field see that the majority of high-quality research grants are not funded, they become discouraged and will loose interest in pursuing careers in research. The whole future of neuroscience research and many potential breakthroughs hang in the balance. Simply put, the current funding crisis takes us in the exact opposite direction from the one in which we need to be going in order to achieve scientific accomplishments in the 1990s.

The Administration's budget for NINDS for FY91 does not correct the situation, and in fact, funding constraints are predicted to be even worse than in the current year. Under the President's request, the number of new and competing grants would continue to decline, with severe cuts in the grant stage still the norm.

We believe that as the appropriations committees take a closer look at current and projected funding constraints on neuroscience research, it will become apparent that a substantial infusion of dollars should be afforded to the NINDS in the FY91 bill, in order to allow us to capitalize on the opportunities in neuroscience research that are on the horizon. With the right kind of federal commitment to neuroscience, achievements in the 90s will do more than increase; progress of an exponential order can be expected.

One area where great strides should be anticipated is in neurogenetics: Advances are anticipated in isolating genes that regulate normal components of the nervous system, and in expanding our understanding of the genetic basis of nerve function. Genes can now be introduced into non-dividing cells--like neurons--and expression obtained. The next logical step is to characterize gene products whose abnormality results in disease manifestation leading to an ability to apply the results of molecular genetics toward development of clinical treatments. Cell transplant therapy has already been successfully conducted in animals genetically deficient for a protein known as dystrophin. The absence of this protein causes muscular dystrophy. Once cell transplant techniques can be perfected for use in humans, we will have a cure for this devastating disease.

Neuroscience research should also be seen as a way to address high health care costs which are attributable to numerous very debilitating diseases affecting the brain and nervous system. Stroke, a leading cause of adult disability which accounts for over $13 billion in health care costs each year, is an important area of opportunity. The situation with regard to stroke is particularly vexing: The mortality rate continues to fall, yet the incidence of stroke is increasing, and with the aging of our population, further increase in incidence is a distinct possibility. The major challenge related to stroke centers on the development of better preventive, diagnostic, and treatment methods. Specifically, the medical management of patients while stroke is occurring is a key research priority. Advanced medical management could mean the difference between someone who returns to the activities of daily living, versus someone who is left paralyzed or speechless and dependent on family and health care services.

In FY 87, the NINDS initiated an effort to place increased emphasis on stroke research. However, since that time, emphasis has fallen off: In FY 90 funding for stroke research within the NINDS was increased only 3.19% over the previous fiscal year. Given that substantial opportunities exist in the field, the AAN is particularly interested in promoting increased attention to, and funding for, stroke research in the upcoming fiscal year. The Congress also has expressed an interest in stroke research. In response to the appropriations committees' requests for information, the NINDS has prepared a report on stroke which outlines the various treatment possibilities now under investigation. It is clear that increased research on stroke treatment and prevention must be undertaken if we are to save lives, reduce disability, and lower the health care costs which are attributable to the occurrence of stroke.

Given that these and other neurological and neuromuscular diseases (including epilepsy, multiple sclerosis and Alzheimer's disease), as well as head and spinal cord injury--have so many exciting areas of promise associated with them, it is no wonder that we call this the "Decade of the Brain". However moving ahead in the decade (which is already a year old) requires an increase in federal support for neuroscience research activities.

The American Academy of Neurology is an organization of over 10,000 neurologists and neuroscientists across the United States and worldwide. Joined by numerous professional, scientific and voluntary health organizations the Academy recommends an increase of approximately $200 million over the current year operating budget for the NINDS for FY 91. This funding level--though a substantial increase--is needed in order to support the increased level of neuroscience research which is available to be conducted in the upcoming year. The recommendation is also consistent with the determinations of the National Advisory Neurological Diseases and Strokes Council in their forthcoming national consensus plan for implementation of the "Decade of the Brain".

There is ample precedent for affording this increase. In the early 1970's Congress provided proportionally larger increases to the National Cancer Institute and the Heart, Lung and Blood Institute, in which areas research was growing especially rapidly. For example in FY 72 Congress appropriated a 66.5% increase to the NCI. While the present funding levels for NCI and NHLBI are $1.66 billion and $1.1 billion respectively, NINDS funding is less than $490 million for FY 90. Because the neurosciences are now where cancer and cardiovascular diseases research were 20 years ago, a similarly sizeable funding increase is justified for NINDS this year. We should not be willing to do any less now than we did then to move science forward. Our ability to exploit these rapidly growing neuroscience research opportunities is directly dependent upon sufficient federal funding.

We are aware that given the national deficit and Gramm-Rudman constraints, the appropriations committees must struggle with limited funds for many important programs. We ask that you look upon the initiative to provide this funding increase for neuroscience research as an opportunity to foster efforts to reduce health care costs associated with neurological diseases, as well as to improve the lives of millions of Americans. We believe that the members of the House and Senate Appropriations committees, to whom the "Decade of the Brain" national consensus plan will be directed, will want to take a leadership role on the funding issue. The Academy looks forward to working with the members of the committee. We would be happy to provide you with any additional information you might desire.

Senator BUMPERS. Thank you very much, Dr. Rosenberg.

Again, I want to say that I am extremely sensitive to your research, and throughout NIH, of course, the number of grants each year is declining, and we are not even coming close to funding the really good, competitive, legitimate grants that we ought to be funding.

Dr. ROSENBERG. Yes, sir.

Senator BUMPERS. Let me ask you a question on a totally unrelated subject that I have thought about for some time. Does your organization or does the American Academy of Neurology or NIH or anybody else, participate and share in research by any foreign researchers?

Dr. ROSENBERG. There are grants which are funded by NIH which go to scientists who are in Canada and, I believe, also to some countries in Europe to a limited degree, yes, sir. Outstanding persons. And their grants do go through the peer review process. The brightest and the best get funded, yes.

Senator BUMPERS. I have often thought that it is like trying to compete with the Japanese where they are not impeded by antitrust laws. We have companies who don't have the resources to put into worthy high-risk ventures. We probably ought to allow some of the companies to pool resources to do that kind of research, and all of them benefit from it.

Dr. ROSENBERG. Right.

Senator BUMPERS. In medical science where we have a world problem such as AIDS, we ought to be participating with foreign countries to pool our resources and ensure that we are performing the very best research possible.

Dr. ROSENBERG. I would agree.

Senator BUMPERS. By the same token, when you consider the fact that we have more applications, really good applications, in this country than we can even begin to fund, it sounds sort of foolish to say that, I guess.

Well, your recommendation is $691 million for 1991; is that correct?

Dr. ROSENBERG. Yes, sir; it is.

Senator BUMPERS. Dr. Rosenberg, thank you very much for being with us today.

STATEMENT OF ALVIN V. BLOCK, PRESIDENT, ESA, INC.

Senator BUMPERS. We will go back to our regular schedule. Mr. Alvin Block, president of ESA, Inc.

Thank you for being with us this morning. Please proceed.

Mr. BLOCK. For 15 years, I have appeared before this committee and others to testify on health issues. Today I bring you a success story, in that new progress has been made in addressing some of the most pernicious neurodegenerative diseases, such as Alzheimer's, Huntington's, and Parkinson's.

My small, 20-year-old company is a key partner in this progress. We have developed a very sophisticated, 16-channel neurochemical analyzer, a computer-driven instrument. Here are some of the details of how our technology applies to these problems.

In Japan, all newborn children are required to be tested for neuroblastoma, a highly malignant brain tumor. Our Coulochem analyzers are the sole instruments used in this testing. More than 4 million infants in Japan have been tested to date.

There is widespread interest in Japan and Europe in neuroscience research. The Japanese are the leading purchasers of our most advanced system, the Neurochem. Other applications of this technology include behavioral studies, nutritional studies, measurement of pesticides and toxic substances, cardiovascular disease, alcoholism, pain, infertility, substance abuse, even the problem of astronauts getting sick in space.

Now the Congress is wrestling with the problems of a health care burden that exceeds $400 billion each year; 20 percent of that burden comes from degenerative disorders. The Director of the National Institute on Aging estimates that 4 million people have Alzheimer's disease, at an annual cost of $80 billion, a drastic increase over 5 years ago, and this cost will grow as the population ages.

I offer three examples of hope. A paper submitted to a scientific journal reports on a possible mechanism of action for Huntington's disease. This paper also suggests a possible course of treatment through modification of diet.

A second development reports how Alzheimer's, Parkinson's, and Huntington's samples were selected from normal controls among 1,500 postmortem human samples, an indication that a diagnostic test is possible.

Finally, a pathfinding paper in the proceedings of the National Academy of Sciences describes how rats afflicted with a Parkinson's-like disease were successfully treated with a genetically modified transplant.

All of this work was possible only because of the availability of our neurochemical analyzer.

Mr. Chairman, I respectfully urge that the Congress direct the National Institutes of Health to fund a program to develop a diagnostic data base for degenerative disorders, including Alzheimer's, Huntington's, and Parkinson's, utilizing the electrochemical array system technology. When considered against the backdrop of 4 million afflicted and an $80 billion cost each year for Alzheimer's alone, the few million dollars needed for this program are insignificant. The benefits are not.

PREPARED STATEMENT

There can be no guarantees, but I believe, Mr. Chairman, that based on research that has already been performed, there is a high probability that inexpensive diagnostic tests can be developed if this program is properly coordinated and funded.

Thank you.

[The statement follows:]

STATEMENT OF ALVIN V. BLOCK

Mr. Chairman

My name is Alvin V. Block. I am President of ESA, Incorporated in Bedford, Massachusetts. For 15 years, I have appeared before this committee and others to testify on health issues.

Today, I bring you a success story. With your indulgence, I would like to tell you how, with the help and faith of the Congress and other government officials, plus a lot of hard work on the part of scientists and engineers at ESA and their research partners at some of America's leading universities and hospitals, new progress in addressing some of the most pernicious neurodegenerative diseases is beginning to unfold.

I speak of Alzheimer's, Huntington's and Parkinson's diseases.

In getting to this point, we have also - to our continuing amazement, I must confess - found that our small, 20 year old company may have significant impact on the possible solutions to a number of other problems of the most wide-ranging sort. I speak of pollution, adulteration of food, even the problem of astronauts getting sick in space.

I offer for the record some details of the application of our proprietary technology to some of these problems, as well as a description of the technology. But with your indulgence, I would like to sketch the story of how this technology sprang to life in the attic of a condemned building in Cambridge, Massachusetts, and how it has grown to be an indispensible tool for cutting-edge research in a number of fields. I will also acquaint you with some sobering news about its application in advanced research in foreign countries and talk briefly of how in my opinion, we need to provide additional support for academic researchers who wish to push the technology to the limit in tackling brain disorders such as Alzheimer's.

The technology is the brainchild of ESA founder Wayne Matson. In 1970 he was a recent MIT Ph.D. with a job as an assistant professor at the University of Michigan. He and one of his students decided to head back to Cambridge to pursue a classic American entrepreneurial dream. They wanted to develop a device to detect and analyze metals polluting the environment at levels a thousand times lower than previously possible. At the time I joined them, as employee No. 3.

At about that same time, the Federal Government asked us if we could find a way to detect lead in very small samples of blood. It was the practice then to extract a full test tube of blood in order to analyze for suspected lead poisoning. We were able to meet that challenge, developing a means for detecting lead poisoning in a single drop of blood. This made it possible to conduct wide screening of children for high levels of lead, with just a prick of the finger or heel. As a result of that research, we were asked by the Centers for Disease Control to become the National Laboratory for all CDC pediatric lead screening programs. We did that work from 1971 until 1982, when Federal funding for lead screening changed from categorical to block grants.

Meanwhile, we put our scientific and engineering expertise to work developing additional instrumentation for detecting and analyzing minute quantities of substance. A number of these instruments are now on the market. In addition, we operate a testing laboratory which provides detection and analysis services for government and industry.

We are fortunate to have been the beneficiary on several occassions of grants under Small Business Administration programs which have been of enormous help to us. We have received more than $1 million to date from this source, which supplemented the more than $5 million invested by ESA in this technology.

During the past ten years, we have focused much of our attention on development of very sophisticated, multi-sensor electrochemical detectors. The most advanced of these is the 16-channel NEUROCHEM^R analyzer, a completely automated computer driven instrument that is performing the biomedical research that I mentioned in the beginning of my talk. Less complex instruments in our electrochemical array family are being used in more routine applications.

Besides those I have mentioned, applications of this technology include detection of cancer, behavioral studies, nutritional studies and measurement of pesticides and toxic substances. Other studies focus on cardiovascular disease, alcoholism, pain, fertility and drug abuse.

In Japan, all newborn children are required to be tested for neuroblastoma, a highly malignant tumor that usually occurs in children under the age of 4. It is found mainly in the adrenals or sympathetic nervous system or in the brain. Our COULOCHEM^R analyzers are the sole instruments used in this testing. Approximately one and one-half million infants are tested in Japan each year with our instruments. More than 4 million have been tested all together. The Japanese government and medical profession have determined that it is cost effective to screen newborns for this disorder and to take corrective action rather than let the disease take its course with its resulting social and financial drain. There is no equivalent mandated program for neuroblastoma in the United States at this time.

Interest in our electrochemical array system technology in Japan is not limited to clinical applications. The Japanese are the leading purchasers of our most advanced system, the NEUROCHEM^R. Japanese purchases exceed those made in the United States. A number of the NEUROCHEM^R instruments have also been purchased in Europe. It seems clear to me that in Japan and Europe, interest in playing a major role in neuroscience research is widespread.

American researchers have flocked to us asking us to run samples for them to test the application of the technology to their research. But many of them report to us later that they cannot purchase the equipment because the inclusion of expensive equipment or instruments on NIH grant applications jeopardizes their approval. Even in industry, the current planning horizons have made implementation of projects to assure food purity difficult. The electrochemical array system technology is expensive to purchase. The most sophisticated instruments sell for more than $100,000. But it is a fair price considering its development cost and its value to a user.

More importantly, it is a price that non-U.S. researchers are very willing to pay.

At the present time, the Congress is wrestling with the problems of a health care burden in the United States that exceeds $400 billion each year. Already, more than 10 percent of that burden comes from degenerative disorders. This cost can be expected to grow as the population ages.

I offer three examples of hope:

- One, a paper currently before a scientific journal for publication reports on a possible mechanism of action for Huntington's disease. This paper offers a possible treatment through modification of diet.

- A second development is a report at the 2nd Annual International Alzheimer's and Parkinson's Conference last fall in Kyoto, Japan, of the ability to select out Alzheimer's, Parkinson's and Huntington's samples from normal controls among 1,500 post mortem human samples - a harbinger, certainly, that a diagnostic test may be possible.

- Finally, a pathfinding paper was published in the Proceedings of the National Academy of Sciences in November that describes how rats afflicted with a Parkinson's-like disease were successfully treated. The scientists, at the University of California and elsewhere, used gene therapy. They transplanted a healthy gene that produces L-dopa to supplant the rats' failed gene, which couldn't produce that essential amino acid.

All of this work was possible only because of the availability of our NEUROCHEM^R analyzer. I must point out, that in each of these cases, we loaned the equipment to the researcher because funds were not immediately available for purchase.

Mr. Chairman, I respectfully urge that the Congress direct the National Institutes of Health to do the following:

Fund a program to develop a diagnostic data base for degenerative disorders - including Alzheimer's, Huntington's and Parkinson's - utilizing the electrochemical array system technology.

Such a program would complement and build upon the research already underway by key research groups across the country. The program would be focused at several of the Alzheimer's disease centers where work is already underway. It is likely that since ESA has developed this instrumentation, that it will be utilized in this program. But even more important is that the program be initiated with the goal of developing a series of diagnostic tests for these disorders. The potential benefits easily outweigh the cost and the risk of failure.

I may be criticized, Mr. Chairman, for urging such a program because my company, ESA, as developer of the instruments that would be used in the performance of this program, would obviously benefit. But Mr. Chairman, this is trivial when measured against the benefits that might accrue to those who are afflicted with these degenerative disorders and who are suffering without hope of relief. A successful program would drastically reduce the 40 to 60 billion dollars annual cost presently associated with these disorders.

There can be no guarantees, but I believe, Mr. Chairman, that based on research that has already been performed, there is a high probability that we can develop inexpensive diagnostic tests that can be utilized routinely if this program is properly coordinated and funded.

Thank you, Mr. Chairman.

Senator BUMPERS. Thank you very much.

Let me ask you: Do the Japanese do this kind of testing for neuroblastoma?

Mr. BLOCK. Yes; they are testing over 1.5 million newborn infants.

Senator BUMPERS. With your equipment?

Mr. BLOCK. With our equipment.

Senator BUMPERS. My question really is do we do it?

Mr. BLOCK. No; it is not a mandated program in the United States.

Senator BUMPERS. Do very many doctors do it routinely, or very many of them—most of them do not?

Mr. BLOCK. I would say most of them do not.

Senator BUMPERS. So the sales of your equipment in this country are not too hot?

Mr. BLOCK. They could always be better. They are reasonable, but the point I would like to make is that we are selling a lot more overseas, and part of the problem is the lack of funding support to people going in for grants asking to purchase the equipment. They are usually turned down.

Senator **Bumpers**. Mr. Block, in Japan where they test infants for neuroblastoma, what do they do if they get a positive result, and what is the instance of positive results?

Mr. **Block**. The latest numbers I saw is about 1 out of every 8,000 children.

Senator **Bumpers**. And what do they do in those cases?

Mr. **Block**. They operate and remove the tumor.

Senator **Bumpers**. Immediately?

Mr. **Block**. They operate.

Senator **Bumpers**. Does that mean that that child has a congenital neuroblastoma?

Mr. **Block**. I cannot answer that. I am not a medical type. I don't know.

Senator **Bumpers**. They do this at birth?

Mr. **Block**. Right at birth, yes.

Senator **Bumpers**. I have never heard of that. That is a very fascinating story.

Mr. **Block**. They place a pad in a diaper and collect urine and then test the urine for some neurochemicals, and if they get positive results, they say, and then they go for further——

Senator **Bumpers**. Is that the only sort of malignant, cancerous condition that they test for?

Mr. **Block**. I doubt it.

Senator **Bumpers**. Can your equipment test for anything else?

Mr. **Block**. I know of another cancer that is being tested for in the United States called fetal chromocytoma, which is a cancer of the adrenal gland which sometimes occurs when someone shows an indication of extremely high blood pressure and it is not from the normal sources of blood pressure, it is due to a particular cancer. That test is occasionally performed in the United States.

Senator **Bumpers**. Really fascinating. My daughter had an astrocytoma, intramedullar, which meant it was embedded in the spinal cord, at the age of two. I have always believed that was congenital, that she had it when she was born. Doctors insist she did not, but I could not help but think, what a miracle that would have been if we had been able to test her for that at birth.

Mr. **Block**. Again, my background is engineering and not medicine or chemistry, so I cannot comment.

Senator **Bumpers**. Thank you very much for being with us, Mr. Block.

Mr. **Block**. Thank you.

STATEMENT OF WILLIAM C. DEMENT, CHAIRMAN, GOVERNMENT AFFAIRS COMMITTEE, AMERICAN SLEEP DISORDERS ASSOCIATION, AND APPOINTEE TO THE NATIONAL COMMISSION ON SLEEP DISORDERS RESEARCH

Senator **Bumpers**. Our next witness is Dr. William Dement, American Sleep Disorders Association, and I am telling you, I have got of personal experiences. You are looking at a guy with a lot of sleep disorders.

Dr. **Dement**. I do not want to say I am very pleased about that.

Mr. Chairman, I represent, as you said, the American Sleep Disorders Association, but when Arkansas had a young and handsome

Governor, the practice of medicine ended when the patient fell asleep.

Senator BUMPERS. Jim Hansen is not young anymore.

Dr. DEMENT. Today there are 3,000 practitioners around the United States, and Arkansas has at least five sleep disorder centers that are flourishing.

About 15 years ago, perhaps 10 doctors pulled back the curtain of the night and revealed the scores of specific disorders that caused complaints, and today we know that about 100 million Americans are afflicted with one or other sleep problem. These include devastating disorders like narcolepsy, described by Mr. Piscopo, and fatal disorders like sleep apnea syndromes and sudden infant death.

In spite of the vast importance of sleep, basic research has not flourished, for lack of a Federal focus. Dr. Dominick Purpura, who testified earlier, said that there were 14,000 neuroscientists studying the brain, and you could add tens of thousands more if you include psychologists, but there are barely 20—20—who are devoting their careers to understanding the fundamental mysteries of sleep. Furthermore, they work in isolation.

In the first and most important step to remedy this situation, as you already heard from Mr. Piscopo, the Congress of the United States has created the National Commission on Sleep Disorders Research, which will have its first meeting next week. Its mandate from Congress is to create the long-term plan for fostering fundamental and clinical research on the sleeping brain.

The single most important issue for this congressional commission is to formulate a specific focus for basic and clinical sleep research in the Federal health apparatus. Any mandate for sleep research will be fruitless, as it has been in the past, if there are not specific and very firm recommendations made by Congress requiring an institutionalized program.

There are two steps which should be started immediately. We recommend the establishment of a program of special centers of research on basic sleep mechanisms and functions. And second, in this congressionally proclaimed decade of the brain that we have already heard described, we request that the Congress make specific recommendations that the National Institutes of Health, including the National Institute of Mental Health, make the sleeping brain a full partner to the waking brain in this effort.

At this very moment, about 2.5 billion people are sleeping right beneath your feet, and some of them are dying because they are asleep.

Senator BUMPERS. How many people?

Dr. DEMENT. Pardon?

Senator BUMPERS. How many people?

Dr. DEMENT. Are sleeping right now?

Senator BUMPERS. Yes; 2.5 billion?

Dr. DEMENT. 2.5 billion. Every time the Earth turns on its axis, you——

Senator BUMPERS. And how many of them are going to die?

Dr. DEMENT. I would say several hundred because they are asleep.

Senator BUMPERS. Is that mostly sleep apnea?

Dr. DEMENT. I would say so. Other things. Many other things.

Senator **Bumpers**. That is interesting. Boy, you talk about a combination in our house. My wife has narcolepsy, and I have apnea. She wakes me up about 10 times a night because she is quite sure I am not going to take another breath, and I have a brother-in-law that died with sleep apnea.

Are we making any progress?

Dr. **Dement**. Tremendous progress.

Senator **Bumpers**. Can I expect to live much longer?

Dr. **Dement**. Oh, yes. There is now a very effective treatment for sleep apnea. It is completely——

Senator **Bumpers**. I went to see a doctor about this, incidentally, and he wanted to do these tests, you know, where you go into the hospital and you sleep.

Dr. **Dement**. That is right.

Senator **Bumpers**. My legislative director did that, and out of 313 minutes, he woke up 297 times, each time gasping for breath.

Dr. **Dement**. Sometimes it goes up to 500, 600, or 700 times. But there is now a very effective treatment, continuous positive nasal airway pressure.

Senator **Bumpers**. What is the most effective treatment?

Dr. **Dement**. It is called continuous positive nasal airway pressure. Very, very slight pressure in the upper airway holds it open and normal sleep is restored, and all of the consequences are obviated. It is available.

The issue, in a way, is that about 80 percent of the people with this problem are still undiagnosed because of the lack of public awareness, the lack of a focus.

So I think what is clear is that sleep is one-half of our existence, if you will, or one-third, and we need to have a focus in this area so that all of the people who have problems can receive whatever benefits are available and that new and better treatments, of course, will be found.

Senator **Bumpers**. It is a fascinating business, isn't it?

Dr. **Dement**. Yes, it is.

Senator **Bumpers**. I wake up most mornings feeling like I just plowed the south 40.

PREPARED STATEMENT

Dr. **Dement**. Well, we can do something about that, honestly. I mean we would like to help you and all the others. I have been in this business for almost 30 years, and I am more fascinated than ever.

Thank you very, very much.

[The statement follows:]

STATEMENT OF WILLIAM C. DEMENT

Mr. Chairman, and members of the Subcommittee, I am very pleased to appear before you today to discuss the importance of sleep disorders research, and basic research on the sleeping brain. I am a professor at Stanford University where I have studied sleep and its disorders for more than a quarter of a century. I am here today to represent the field of sleep research and sleep disorders medicine as Government Affairs Chairman of the American Sleep Disorders Association, and founding President of the Association of Professional Sleep Societies. This national association is comprised of the Sleep Research Society, the American Sleep Disorders Association, and the Association of Polysomnographic Technologists. As of this year, we have grown to over 3,000 specialists around the country who are engaged in the practice of sleep disorders medicine, or who are carrying out research on sleep, fatigue related catastrophes, or clinical sleep disorders.

I would like to begin this discussion by enunciating three fundamental principles which underly the true nature of sleep.

- The first principle is that sleep is an active process. When we sleep, our brains are just as active as when we are awake, and frequently very much more active. The quiescence of the body during sleep is therefore a very misleading indicator about what the brain is doing.

- The second principle is that the sleeping brain works in a way that is very different from the waking brain. One way to formulate this principle is to think of the brain as a marvelous computer with two totally different operating systems. This fundamental principle explains why it is possible to be healthy when awake and separately ill when asleep.

- The third principle is that the activity and function of the sleeping brain are purposeful and vitally necessary. We cannot live without sleep. Deprived of all sleep, organisms deteriorate and die.

I cannot over emphasize that the sleeping brain is as active as the waking brain, but works differently, and has its own unique and vital tasks to perform.

My most important message! The active, working, sleeping brain is not working properly in more than 100,000,000 Americans.

How does the sleep brain fail? Here are some examples:

- Sleep apnea syndromes: About twenty varieties of a fundamental and deadly problem having various degrees of progressive severity afflict and sometimes kill more than twenty million Americans.

- Sudden Infant Death Syndrome: More than 7,000 infants yearly die suddenly, unexpectedly and tragically in their sleep because the immature sleeping brain cannot reliably maintain the life support systems.

- Narcolepsy: The sleeping brain is unable to accomplish the nightly task of restoration. As a result, more than 250,000 Americans afflicted with this illness cannot ever be fully awake.

- Insomnia: The sleep of thirty million Americans is habitually fragmented and disrupted by this sleep disorder.

- Stroke, epilepsy, and heart attacks: Something about the nature and timing of the sleep period predisposes one to the occurrence of these medical catastrophes.

- The aging of sleep: The prevelances of nearly all sleep pathologies and problems increase exponentially in the elderly. What is quality of life lived in a haze of fragmented sleep and crippling daytime drowsiness?

In addition, we poison the delicate machinery of the sleeping brain with illicit drugs and alcohol, and abuse its exquisitely timed daily rhythms with a chaotic regime of abnormal work schedules and jet travel.

Finally, at the most basic level, we simple do not allow ourselves to get enough sleep at night because the general public is unaware of the facts of promoting healthy sleep and wakefulness including the specific amount of sleep that is needed each night to be wide awake and energetic during the day.

Sleep disorders, and sleep related phenomenon are a substantial part of the total health picture. Those of us who occasionally experience sleeplessness over a period of a night or two cannot relate to the individual who experiences nightly sleep apnea episodes, causing him to wake up literally hundreds of times a night gasping for breath with accompanying cardiopulmonary distress. Or to the narcoleptic patient who even against his or her will, falls asleep while eating dinner, or talking, or driving on the freeway at 55 mph. Other sleep disorders include nocturnal myoclonus, a strange, periodic and intermittent movement of the legs that also disrupts sleep hundreds of times a night. More familiar to many are insomnia, nightmares, and night terrors. Most often individuals with chronic sleep disorders need diagnosis and treatment by specialists who are thoroughly trained in the principles and practices of sleep disorders medicine.

In the past two decades, a small group of sleep research pioneers focused their efforts on the comprehensive nocturnal evaluation of patients. A host of illnesses were discovered that were previously unknown. The Association of Sleep Disorders Centers, an organization of facilities and specialists which provide diagnosis and treatment for patients with sleep disorders, was founded in 1975. In the absence of a specific NIH mandate and federal funds and any other outside support, a new clinical specialty, sleep disorders medicine, whose task is to diagnose serious sleep problems and provide the best available treatment, was created.

The field has been most successful in treating sleep related problems that cause excessive somnolence during the day, such as sleep apnea and narcolepsy. You probably are aware that most major cities around the U.S. have one or more accredited Sleep Disorders Center, usually affiliated with a major medical center. We estimate that 400,000 to 500,000 Americans annually seek medical diagnosis and treatment for the sleep disorders I have just mentioned. However, at the present time, it is likely that 90% or more of patients with serious sleep disorders remain undiagnosed and untreated.

The clinical practice of sleep medicine has undergone explosive growth since 1980. Yet on the other hand, research on the sleeping brain has been shriveling. Today, it is ironic that there are almost no scientists working on its basic mechanisms and functions when we can bring to bear the most advanced techniques of molecular biology, neurochemistry, neuroanatomy, and neurophysiology to some other mysteries of sleep. On the other hand, there are more than 20,000 scientists working on the waking brain. This represents a major imbalance in the allocation of research resources, and a serious neglect of one of our most important areas of basic research. Mr. Chairman, I cannot count twenty scientists in the entire United States who are saying, "I want to devote my life to research on the mysteries of the sleeping brain." The reason is simple. Students and young investigators have not been attracted into the field because there are no clear career pathways for talented basic sleep researchers, and with no place in the establishment, there are two strikes against them in the peer review system of competing for research grants.

Generally speaking, the biggest obstacle for basic and clinical sleep research has been lack of "designated responsibility" within the Department of Health and Human Services (HHS). Research in sleep disorders cut across all medical disciplines. Yet, no established discipline or institute has been willing to take complete responsibility for the sleeping brain.

In the vast health, transportation, military, and regulatory bureaucracy of the federal government there is not one institute, one committee, or even one person charged exclusively with the task of fostering our understanding of the sleeping brain, or of promoting research on its illnesses. Sleep disorders will affect essentially every living person at one time or another, and certainly every doctor will encounter many patients with serious sleep problems.

Speaking for all sleep disorders clinicians and researchers and all our patients, I am here to say that we must have basic and clinical research on the normal and abnormal sleeping brain. We must understand its workings and its illness. With as much urgency as possible, I say that the mysteries of the sleeping brain are as worthy as the mysteries of the atom, the gene, and yes, the waking brain.

What has been accomplished with the help of the Congress?

Mr. Chairman, I am happy to note that federal and public policy makers are beginning to recognize the health and safety issues related to sleep pathology. A number of outstanding federal initiatives are taking place currently that I wish to review with you and the subcommittee, and also express our thanks to you for facilitating this activity.

The National Heart, Lung and Blood Institute (NHLBI) has initiated a program of three Special Centers of Research on Cardiopulmonary Sleep Disorders. These Centers support multidisciplinary studies that integrate basic sleep research as it relates to the regulation of the heart and lungs during sleep. The NHLBI has also begun to explore the feasibility of initiating a multi-center controlled clinical trial to determine if sleep apnea imparts significant morbidity and mortality and whether its consequences can be reversed. It is important to initiate additional funding for this program.

The National Institute on Aging (NIA) and the Office of the Medical Applications of Research (OMAR) are planning to sponsor a national consensus development conference on Sleep and the Aging that will bring together experts from the fields of sleep research and other geriatric disciplines to discuss sleep disorders among the elderly and come to consensus on the most appropriate methods of dealing with these issues. The NIA has an excellent record in supporting meritorious geriatric sleep research. This conference is to be held this month.

The National Institute of Neurological Disorders and Stroke is planning a major, International Symposium on Narcolepsy Research that will bring in top researchers from around the world who are involved in sleep related disciplines. The hope is that these scientists will develop an interest in the fascinating challenge presented by narcolepsy research, and the conference will stimulate these scientists to study this important disorder.

The congressional Office of Technology Assessment has established a panel of distinguished experts to study biological rhythm disturbances and sleep disorders in the work place and to make recommendations. It is well known that jet lag and shift work create both a hazard and a reduction of the quality of life for millions of Americans.

The Health Care Financing Administration has asked the PHS Office of Health Technology Assessment to initiate the review of current guidelines that Medicare carriers use to determine appropriateness of treatment for purposes of reimbursement. This review should lead to the development of more modern, up-to-date guidelines, that would replace the current ones that were developed decades ago.

The Department of Transportation has been requested by the Appropriations Committees to develop a plan for research to understand the role of sleepiness and fatigue in transportation accidents. These results will have vast applications in all work-related situations including hospitals, nuclear power plants, and the military.

The Institute of Medicine of the National Academy of Sciences has recently carried out one of its prestigious "research briefings" to examine the topic of basic sleep research. Its forthcoming report will identify outstanding research opportunities and make recommendations on how best to achieve them.

And, the best of all, Mr. Chairman, Congress has established a National Commission on Sleep Disorders Research which has the mandate to establish a long range plan for fostering basic and clinical sleep research, the medical applications of this research, education and training, and widespread information dissemination to professionals and the general public. The commission will make recommendations for the overall administrative structure and organization for sleep disorders research through NIH and other federal agencies. I have been asked to serve on this important commission that was appointed by the HHS Secretary. The first meeting is next week. The commission, in about a year and a half will be before the Congress with their long range plan.

What can and should be done in the future?

Of the billions and billions of dollars expended for health, 99.9% go to promote the waking half of our existence. We must continue our work to elevate the sleeping brain and its many illnesses to a status more equal to the waking brain.

The second step is a federal research policy mandate. There must be a clear statement that is in the best interest of the American public to carry out research on the problems of the sleeping brain including its fundamental nature.

Representing the community of sleep specialists, we would strongly recommended a specific focus for basic and clinical sleep research. Any mandate for sleep research will be fruitless, as it has been in the past, if there is not specific and very firm recommendations made by Congress requiring an integration of these efforts through the government. This process has already been initiated via legislation creating the National Commission. This body will consist of professionals whose primary expertise is in sleep research and sleep disorders medicine, federal representatives, patients, and citizens whose clear mission is to create the national long term plan for fostering sleep disorders medicine and research on sleep and its disorders.

Meanwhile, we believe that it is essential to continue the programmatic progress that we have been making during the past several years. To facilitate this progress, a proposal has been developed which details the need, objectives, and justification for the establishment of a program of Special Centers of Research on Basic Sleep Mechanisms and Functions. Concern for the health of millions of Americans demands that we close the tremendous gaps in basic knowledge about the activity of the sleeping brain. The establishment of such a program of basic sleep research would be a crucial step in this endeavor, thereby allowing basic sleep research its essential place at the research table and assuring the preservation of our valuable research resources. Mr. Chairman, it is vital that we study the basic mechanisms of sleep and the vital functions of the sleeping brain. In this congressionally proclaimed "Decade of the Brain", it would indeed be timely to target the secrets of the sleeping brain with an integrated attack deploying the full range of new technologies and skills that are available in the many disciplines related to sleep. Mr. Chairman, in order that such an initiative be superbly planned, we request that the Congress make recommendations that NIH move forward with the establishment of a plan to implement this program. This important step does not need to wait for the report of the National Commission.

Sleep disorders medicine and study of the sleeping brain is now a fully mature discipline, and absolutely must have its independence. Independence requires a means of education and training leading to discipline identity and faculty positions, a means of support, and a special recognition of the exciting research opportunities and their enormous potential benefit to humankind. Beneath your feet, on the other side of the globe, 2 billion people are trying to sleep. Many are dying because of problems that they have with sleep. Healthy sleep is a blessing; pathological sleep is a curse.

Mr. Chairman, thank you for the opportunity to present the views of the American Sleep Disorders Association. I will be pleased to respond to questions.

Senator BUMPERS. Dr. Dement, the budget carries no recommendation for any increases for research centers, program projects or the three centers. Could you give me an estimate of what you think the increase ought to be for these things?

Dr. DEMENT. Well, we think it should be at least doubled, but I think we are also hoping through the National Commission to study this in a very precise way so that we can understand how many sleep centers should be established in the United States, how many new scientists need to come along to give this vast area the place it deserves, and I think we will be coming with recommendations to Congress within 1 or 2 years. We hope to work very closely with Congress in this area.

Senator BUMPERS. Incidentally, so far as sleep apnea is concerned, weight is a problem, too, isn't it?

Dr. DEMENT. Yes; there are a number of risk factors. Gender is a risk factor, age and weight.

Senator BUMPERS. Drinking?

Dr. DEMENT. Drinking, and upper airway anatomy, but there is a fundamental problem in the brain itself in terms of regulation of respiration during sleep. The sleeping brain is active, and it regulates the vital processes in a different way than when it is awake. And it is that area that needs to be understood better to deal with those.

Senator BUMPERS. How many people in this country, or what percentage of the people would you say suffer from a sleep disorder of one degree or another?

Dr. DEMENT. I would say, if you range from the merely troublesome to the devastating, 40 percent. Like 10 percent have sleep apnea, 20 percent have serious insomnia, maybe 500,000 have narcolepsy. If you add jet lag, shift work, and impaired alertness due to sleepiness, it is just millions and millions and millions.

So I think here I have listened to the Appropriations Committees deal with the issues of the competitive needs, but this is an area that is vast and is still close to zero in terms of its Federal funding and its focus.

Senator BUMPERS. When was narcolepsy first diagnosed, first discovered?

Dr. DEMENT. Well, it was at least as far back as 1880, and I would say its pathophysiology began to be understood in around the 1960's incompletely. And it has been the focus of some research only very, very recently.

Senator **Bumpers**. Dr. Dement, I wish I had longer to spend on all these witnesses, but I guess we have to get going. But I do thank you very much for your work and certainly thank you for being with us today, and we will see if we can help out.

Dr. **Dement**. Thank you very much.

STATEMENT OF KENNETH W. WHITTINGTON, PRESIDENT, AMERICAN ACADEMY OF FAMILY PHYSICIANS

Senator **Bumpers**. Our next witness is Dr. Kenneth Whittington, president of the American Academy of Family Physicians.

Welcome, Dr. Whittington.

Dr. **Whittington**. Senator Bumpers.

Senator **Bumpers**. Please proceed.

Dr. **Whittington**. Thank you.

I am Kenneth Whittington, president of the American Academy of Family Physicians, 68,000 members strong across the United States, representing practicing family physicians, residents, and medical students.

We deeply appreciate the support in the past of your subcommittee on family practice support grants. These support programs have been able to allow us to train residents to become family physicians, to increase the development of our faculty in medical schools, and to increase our interest in medical students.

Your continued support is very critical this year. Once again, we are faced with a proposed budget from the administration which has totally cut out all the funds for these important programs; 93 percent of our practicing family physicians are on the front lines seeing patients. We are seeing patients from newborns to elderly, from urban areas to rural areas, from inner-cities to outposts in America.

We see the social problems that are very prevalent in our society today, such things as teenage pregnancy, infant mortality, and the AIDS epidemic that we see going through the country. Our physicians that see these people treat about 85 to 90 percent of those ailments, so it is a very, very cost-effective health care delivery.

We are not keeping up, sir, with the demand that is needed for family physicians in this country. The projection in the next 15 years shows the increase in physicians in the United States of about 22 percent, yet only about 9 percent increase in family physicians, and we think this is woefully low.

Last year, with the support of this subcommittee, Congress appropriated $33.3 million for the family practice residency programs, and $6.8 million to our family practice departments. We appreciate your past support, and again, we request family practice training be a priority for the targeted health professions training grants.

We would encourage your subcommittee to fund family practice education at the levels authorized: that is, the $40 million for the residency programs and the $7 million for the departments of family practice.

These grants help offset some of the financial disadvantages that we experience in family practice education programs, in the fact that over two-thirds of our programs are in community hospitals, away from tertiary care medical centers.

PREPARED STATEMENT

Because of this, we are looking at different areas of training our residents also, such as affiliating with community health centers, migrant health clinics, and free clinics, so that our residents come out and they know how to do preventive medicine and do it in a style that is more economic for the care of the people of America.

We urge the full support, if we might, this year, sir.

[The statement follows:]

STATEMENT OF KENNETH W. WHITTINGTON

FUNDING FOR FAMILY PRACTICE TRAINING PROGRAMS

I am Kenneth W. Whittington, M.D., President of the American Academy of Family Physicians. The Academy is the national medical specialty society representing 68,000 practicing family physicians, family practice residents and medical students. I am pleased to have the opportunity to appear before this subcommittee to discuss with you appropriations for Fiscal Year 1991 for family practice education.

The Academy is appreciative of your recognition of the need for and the contribution of the specialty of family practice to the nation's health care. Assistance through federal grants targeted to Family Practice Residencies and Departments of Family Medicine help to train more specialists in family medicine and increase access to quality health care for Americans. Your continued suppport is critical as we again face a budget which would eliminate support for family practice training, as proposed by the Administration.

THE NEED FOR MORE FAMILY PHYSICIANS

Approximately 93% of family physicians are engaged in direct patient care, serving the range of the nation's population from its children to its elderly, from its urban to its rural areas. It is these physicians who make the initial diagnosis and provide the continuum of care for patients with a variety of health and social problems, such as teenage pregnancy, infant mortality and human immunodeficiency virus, as well as problems involving occupational and environmental health. Because of their multidisciplinary training, family physicians are able to care for the majority of the problems that present in their offices and are particularly adaptable to the diverse needs presented in the various geographic areas.

Graduates of family practice programs serve the medically needy in remote rural areas as well as impoverished inner-city areas. Family physicians locate in shortage and rural areas in larger proportions than other medical specialties, thus helping to address the national problem of geographic maldistribution.

As the demographics of the U.S. population change, many more family physicians will be needed and must be trained. The population 65 years of age and over will increase about 2 percent a year between now and 2020. These elderly will require a wide range of health care services, including preventive, primary, long-term, hospice, and rehabilitation care. Over the next decade there must be a substantial increase in the number of family physicians to meet the demand for health care.

SUPPLY OF FAMILY PHYSICIANS

While the demand for family physicians is high and growing, the supply is not keeping pace. Data from the AMA physician Masterfile indicate that between 1975 and 1986 the overall active physician population increased by almost 45%. In contrast, the active family physician population, including general practitioners, grew by only 24%. During the next 15 years the AMA projects that the total physician population will increase by nearly 22%, while the number of family physicians is projected to increase only 9% by the year 2000. Concurrently, the number of family physicians/general practitioners retiring from medicine will increase during this period.

THE NEED FOR MORE FAMILY PRACTICE TRAINING PROGRAMS

Last year with the support of this Subcommittee, Congress appropriated $33.350 million for family practice residency training and $6.8 million for departments of family medicine within medical schools. We have appreciated your past efforts and again come to you requesting that family practice training be a priority for targeted health professions training grants. The authorization levels for support of family practice training programs would provide $7 million for departments and $40 million for residency programs. We would encourage this subcommittee to funding family practice education at the levels authorized.

These funds provide support to train residents to become family physicians, to develop faculty in the specialty of family practice, to create and strengthen departments of family medicine within medical schools to ensure that students are exposed to family practice as a viable career choice. The federal grants help to offset some of the financial disadvantage experienced by family practice education programs.

Over two thirds of family practice residency programs are located in community hospitals, rather than in traditional tertiary medical centers. In addition to the community hospitals, family practice residency programs are exploring affiliation with community health centers, migrant health centers and free clinics. Location in non-traditional training sites, coupled with an ambulatory-based training model which emphasizes training in a family practice center to simulate practice in a physician's office, provide these residency programs with significant financial challenges.

In 1970 there were 49 approved residency programs with 290 residents. Tremendous growth in family practice followed and then peaked in 1983 with 388 residency programs and 7409 residents. Today there are slightly fewer programs and family physicians being trained, 384 programs and 7392 residents. The growth curve in family practice education closely parallels federal support of these training programs. Continued federal support is essential to sustain the progress made to date.

Another important source of federal funding is that provided through the Medicare programs. Of concern to the Academy are the provisions in the Administration's Fiscal Year 1991 proposed budget to reduce graduate medical education assistance. The proposed budget calls for savings of $1,040 million in indirect medical education payments and $205 million in didrect medical education payments. Fragile primary care training programs may become less attractive as hospitals evaluate their commitment to medical education programs.

SUMMARY

The federal support of family practice training programs has helped to bring quality health care to many people who otherwise might not have a physician in their communities. However, while the demand for family physicians is growing, there has been a standstill in funding for these programs and in their growth.

We are, therefore, seeking funding for these programs at their authorization level. The authorized levels are $7 million for departments of family medicine (Section 780) and $40 million for family practice residency programs (Section 786) for FY 91. We encourage your support of this funding and look forward to continuing to work with you on appropriations for Fiscal Year 1991.

Senator **Bumpers**. You get it from me. Again, that was one of the things I established when I was Governor, and that was the residency program in family practice. That has grown. I see where you say it went from 49 in 1970 to about 200-plus in 1983. Ours was one of the increases. I am very sympathetic.

One question. You know, the administration has proposed zapping both of these programs.

Dr. **Whittington**. Yes, sir.

Senator **Bumpers**. Does the administration propose to get money for this program from some other source, or are they just zapping the program?

Dr. **Whittington**. My understanding is it is just cutting it totally out, sir.

Being a practicing family physician from Oklahoma, a neighboring State of yours, we do know how interested you have been in family practice, and we need more physicians if, indeed, we are going to take care of the access problem that we have in this country.

Senator BUMPERS. Access is a big, big problem. That is the reason I did what I did. I took a poll and found that 50 percent of the people in Arkansas did not know what to do if they woke up with chest pains.

Dr. WHITTINGTON. That is right.

Senator BUMPERS. Didn't know where to go, who to call, nothing.

Dr. Whittington, thank you very much for being with us.

Dr. WHITTINGTON. Thank you, Senator.

STATEMENTS OF:

DR. RONALD J. QUINN, DEAN OF GRADUATE SCHOOL, SOUTH CAROLINA STATE COLLEGE, AND REGIONAL RESOURCE CENTER DIRECTOR OF THE NATIONAL ALLIANCE FOR MINORITY GRADUATE AND PROFESSIONAL EDUCATION, INC.

JAMES SMITH, CHEMIST AT PROCTER & GAMBLE, FORMER PATRICIA ROBERTS HARRIS FELLOW FROM MISSISSIPPI STATE UNIVERSITY

Senator BUMPERS. Our next witness is—I see we have two witnesses, Dr. James Smith and Dr. Ronald J. Quinn, dean of the South Carolina State Graduate School, National Alliance for Minority Graduate and Professional Education.

Drs. Smith and Quinn. Please proceed.

Dr. QUINN. Senator Bumpers, I am Ron Quinn, dean of the Graduate School at South Carolina State, and it is a rare opportunity for a graduate dean to give pleasure and relief to a potential audience by notifying them at the outset that I am not going to speak.

It is my duty today and it is a distinct pleasure to introduce a finished product of the Patricia Roberts Harris Minority Fellowship Program, which I represent, to speak on behalf of its adequate funding.

Dr. James A. Smith is a 1985 Ph.D. graduate in analytical chemistry from Mississippi State University, and he is now successfully applying at Procter & Gamble what the Harris program and you, through congressional support, have helped him get.

Dr. Smith.

Senator BUMPERS. Please proceed, Dr. Smith.

STATEMENT OF JAMES SMITH

Dr. SMITH. Thank you.

I believe there are two root causes of problems in minority graduate education that the PRH Fellowship Program works to correct, both economics and the sociopolitical environment of graduate schools.

There is a tendency for minorities who achieve bachelor's degrees to stop at this point and to get a job making more money than anybody in their family ever did. I was coached by faculty members, actually, to seek an advanced degree, so I was lucky.

But what about the cost? I had already incurred significant debt in student loans, besides burdening my parents with the cost of a college education. Faculty members clued me into teaching assistantships, which are good. However, these assistantships defocus graduate students from doing research and obtaining their degree.

Another root cause of problems in minority graduate education is their—minorities', I mean to say—lack of understanding of sociopolitical environments of graduate schools. There are unwritten rules that minorities just are not privy to.

For example, I began my graduate career at the University of South Carolina. Foolishly, I stated to the faculty that I wanted a master's degree in chemistry. I did not know at this particular school a master's degree was a second prize reserved for those who could not qualify for a doctoral degree. Learning these kinds of things takes time.

Having a GPOP fellowship, as it was called back in 1982, made the difference in attainment of my Ph.D. in analytical chemistry. Essentially, it relieved the economic burden, allowed me to focus my time on research and understanding the graduate culture. I finished the Ph.D. program in slightly less than 3 years, where the normal span is 5 to 6 years.

Six publications and numerous presentations at scientific conferences supported by the fellowship resulted from this work. Additionally, the patent rights for invention from this work were sold to a corporation.

Immediately after receiving my degree, I started a career at Procter & Gamble as a research scientist. On the side, I have been involved in recruiting minorities. We at Procter & Gamble try to hire at least two to three black Ph.D. researchers a year. However, we have been hampered by the lack of candidates.

When I received my degree, I was the only black analytical chemistry Ph.D. produced in the Nation over a 3-year period. Industry and academia are ready to hire these individuals and provide researchers to attack the problems that were mentioned here earlier today. There are simply too few.

PREPARED STATEMENT

I want to thank you and the Government for funding this program. I am the only Ph.D. in my family tree, which has been traced to pre-Civil War days. I come from a family of three children raised in a three-bedroom clapboard house. The PRH fellowship has allowed me to significantly improve the quality of my family life and myself. So thank you very, very much.

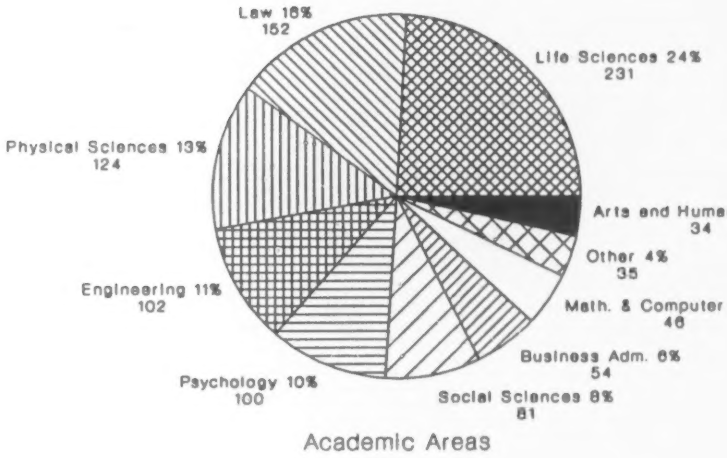
[The statement follows:]

STATEMENT OF RONALD J. QUINN

Mr. Chair and Members of the Subcommittee, I am pleased to present testimony to you today in support of adequate funding for the Patricia Roberts Harris (PRH) Graduate Minority Fellowship program, and other programs supporting Minority Graduate Education.

Mr. Chair, the nation and higher education face a crisis in the underproduction of minority individuals achieving doctoral degrees. The PRH program is the major federal commitment currently addressing this crisis. The Patricia Roberts Harris Graduate Minority Fellowship program (formerly known as the Graduate and Professional Opportunity Fellowship program) authorizes the Secretary of Education to award discretionary grants to institutions of higher education to assist minorities and women to undertake graduate and professional study in fields in which they have been traditionally under-represented. The Department allocates fellowships on a competitive

PATRICIA ROBERTS HARRIS
FELLOWSHIP PROGRAM FOR 1988

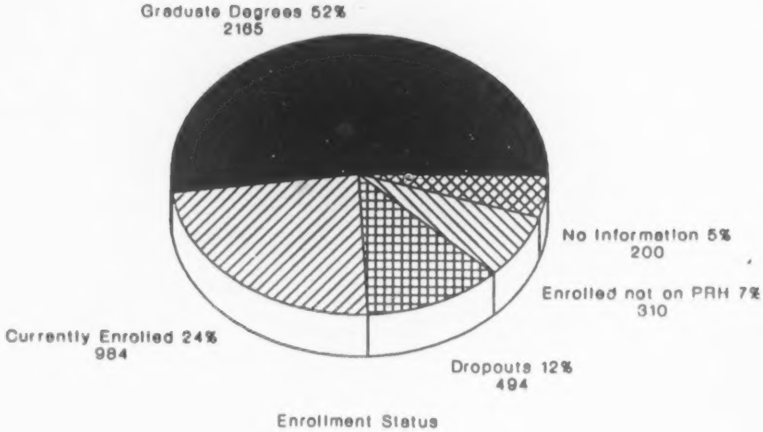


source: U.S. Department of Education

basis to institutions with doctoral and professional degree programs in which there is a national need for highly trained individuals. The institutions, in turn, recruit individuals from under-represented groups and award fellowships to students who demonstrate financial need and who plan to pursue advanced degrees in approved academic areas.

In 1985-86, minority group representation in the program included: African Americans (41%), Hispanics Americans (21%), Asian Americans (11%), Americans Indians (6%), and European American females (21%). Women, overall, comprised more than 50 percent of the 1,417 fellows supported during academic year 1985-86. It is very questionable whether these individuals would have pursued graduate study without this program. Students studying in the fields of engineering and the physical and life sciences received over 50 percent of the fellowships awarded in 1985.

Patricia Roberts Harris Fellowships
From 1978 to 1988

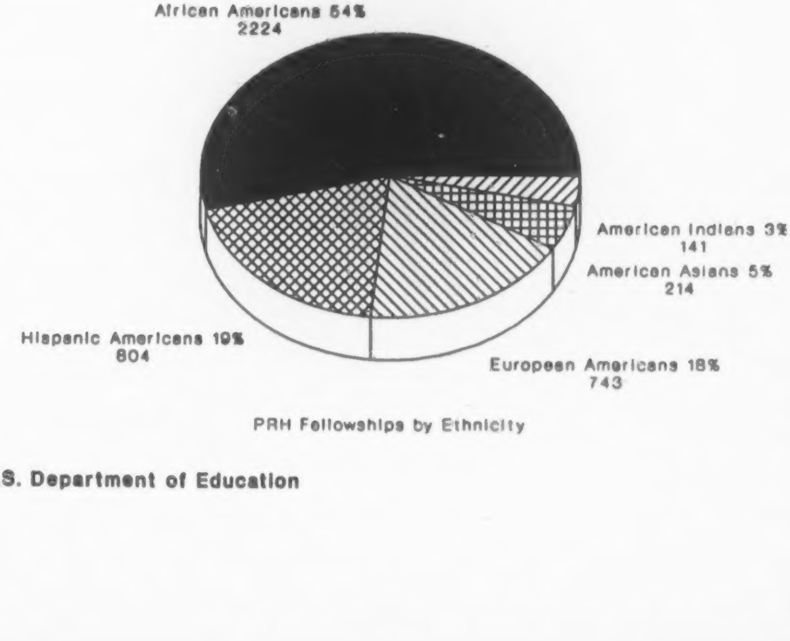


Source: U.S. Department of Education

From 1978 to 1988 the PRH program has assisted over 4,100 minority individuals and women in their pursuit of graduate or professional degrees. Over 2,000 minority and women students have completed graduate or professional degrees with the help of the PRH program. Many more minority and women students became interested in graduate programs as a result of the PRH Program. Mr. Chair in 1977, 684 African American men completed doctoral degrees, but in 1988, only 311 African American men completed the earned doctoral degree; A fifty-four percent decrease in the production of African American male Ph.D. recipients. Since 1978, the PRH program has addressed this crisis by assisting over four thousand minority individuals in their pursuit of graduate and professional degrees.

At Mississippi State University, Mr. Quiton Booker (D.B.A. - Accounting), Mr. Nathaniel Keys (Ph.D. - Horticulture), Mr. Keith Parker (Ph.D. - Sociology), Mr. James Smith (Ph.D. - Chemistry), Mr. Kenneth Stallings (Ph.D. - Poultry Science), and Mr. Floyd Woods (Ph.D. - Horticulture) were able to complete their graduate degree programs with the help of PRH fellowships. It is unlikely that these African American men could have financed their graduate education without the support of a PRH fellowship. From 1978 to 1988 over 4000 PRH fellowships have been awarded. African Americans (54%), American Indians (3%), American Asians (5%), European American (18%), and Hispanic Americans (19%) have been represented as recipient of PRH fellowships. The PRH has a very low dropout rate. Less than 15% of PRH

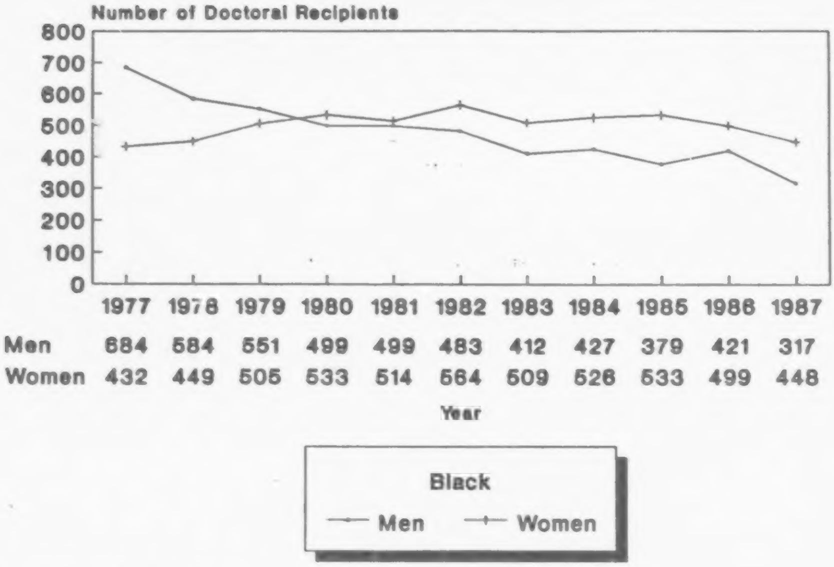
Patricia Roberts Harris Fellowships
From 1978 to 1988



PRH Fellowships by Ethnicity

Source: U.S. Department of Education

Doctorate Recipients
By Sex, Race, and Citizenship



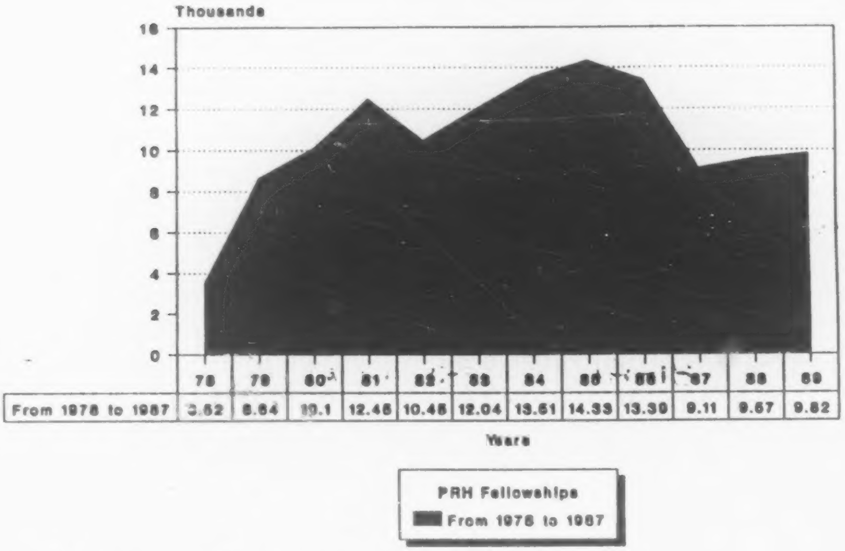
	1977	1978	1979	1980	1981	1982	1983	1984	1985	1986	1987
Men	684	584	551	499	499	483	412	427	379	421	317
Women	432	449	505	533	514	564	509	526	533	499	448

Source: National Academy Press

fellows have terminated their degree program without a degree. Nationally, graduate school dropout rates are estimated to be as high as fifty percent. As you can see, Mr. Chair, this program, while modest in the scope of the entire education budget, represents a very significant contribution in resources to continue opportunities for minority students and for the institutions that train these students.

For Patricia Roberts Harris Graduate Fellowships for FY 1991, the President has recommended $17.78 million, an increase of $1.746 million over the current FY 1990 level. This would not restore the PRH program to the number of fellowships it supported before the new Higher Education Act was reauthorized in 1986.

Patricia Roberts Harris Program
Overview



Source: U.S. Department of Education

The Higher Education Act Reauthorization of 1986 modified the Graduate Professional Opportunity Program by redesignating it as the Patricia Roberts Harris Fellowship Program. The Program was significantly improved by increasing the level of each fellowship to $16,000 per year from the level of $8,400 per year. This program improvement, however, created a significant gap in the Education Department's ability to continue to fund the same number of fellowships at the increased rate. Because of the increased stipend level, an increased appropriation is necessary for FY'91 to restore the number of fellowships to the pre-1987 level. If just the current level of funding were maintained, the number of fellowships available to support minority individual and women would be approximately reduced by one-third the number that was available before the 1986 enactment of the Higher Education Act.

An FY'91 appropriation of $23,300,000 would allow restoration of fellowships to the FY'86 level of 1,400 and provide the higher stipend Education Act Amendments of 1986. Among these fellowships about 500 would be new and would assure a continuation of progress for minorities seeking graduate education. It is likely, if funding for this program is not increased significantly that new fellowships would decline for several years, thus, severely undermining the intent of the program and eliminating a great number of opportunities for African Americans and other minorities who wish to seek graduate professional education.

Mr. Chair, we have listed below, in chart form, the status of the program, and our recommendations. Currently in FY'90, there is a significant decrease in the number of fellowships being funded compared to previous levels. The recommendations that our organization makes will restore the number of fellowships to 1,400.

	FY'86	FY'89	Proposed FY'91
Funding	$11,250,000	15,711,000	23,300,000
Fellowships	1,428	1,011	1,400

Minority Participation in Graduate Education

Mr. Chair, another critical initiative that needs additional support is the Minority Participation in Graduate Education program. This program provides fellowships assistance to encourage and help prepare talented and needy minority undergraduate students to pursue graduate study. We support the President's request of $6.094 million for FY'91.

I am pleased to respond to any questions you have.

Senator BUMPERS. Thank you very much. That is a splendid statement, and we appreciate very much your being here.

I see the program was significantly improved by increasing the level of each fellowship to $16,000 per year, from $8,400 per year. When did that occur?

Dr. QUINN. Just after Dr. Smith graduated. He graduated in 1985, and that began in 1986. But even when it was lower, he was able to do the marvelous job that he has done.

Senator BUMPERS. You know, I have to confess this is a new program to me. I am not familiar with this. But based on the testimony here and the charts ~~and~~ graphs I am looking at, it has been fabulously successful.

Dr. QUINN. Sir, I think it is one of the best, although it is still very small when you consider the number that we are funding.

Senator BUMPERS. This is one of the few programs, to the President's credit, that he has recommended some increase in.

I am deeply concerned about the lack of minorities in graduate programs, and undergraduate programs, for that matter, and we simply must address that. This looks to me like it is certainly one good way to do it.

I think one of the reasons the minority enrollment is declining is the same reason a lot of majority students are having a tough time, and that is that debt they come out with. Minority students are certainly much more likely to have to go for guaranteed loans and, therefore, owe a lot more. It is such a disincentive.

Well, thank you both very much for being with us today. The best of luck to you.

STATEMENT OF DR. I. BERNARD WEINSTEIN, DIRECTOR, COMPREHENSIVE CANCER CENTER, COLUMBIA UNIVERSITY, AMERICAN ASSOCIATION FOR CANCER RESEARCH, INC.

Senator **Bumpers**. Our next witness is Dr. I. Bernard Weinstein, director, Comprehensive Cancer Center, Columbia University, representing the American Association of Cancer Research.

Dr. **Weinstein**. It is a pleasure to appear before you to represent the American Association for Cancer Research, this Nation's major cancer research organization encompassing about 6,000 members, scientists, and clinical investigators spread across this country. My own area of research is concerned with cancer causation and prevention, and there are very exciting opportunities to now make a major impact on this disease.

We honestly appreciate the support of your committee and also the fact that the National Cancer Institute provides 90 percent of the total research dollars for cancer research in this country. At the same time, I am impelled to tell you that our association, cancer investigators, the entire biomedical community across this country faces a very serious crisis in terms of inadequate financial support of cancer research and other biomedical areas that you have heard about today.

Let me portray for you in personal but real-life terms the nature of this disease. A 45-year-old woman was admitted to our medical center a few years ago with a large mass in her left breast. Diagnostic studies indicated that she had a highly malignant cancer that had already spread to lymph nodes and to liver. Because of poor cancer detection programs and lack of their availability to large populations, she had neglected to go to a doctor early on when the lesion could be treated. Initially the tumor responded to therapy, but later it recurred. She died within 2 years of diagnosis. Autopsy revealed extensive invasion of the tumor in the liver, brain, and skeleton.

This tragic death is not a rare episode. Each year over 40,000 American women die a similar death of breast cancer, and each year over 140,000 new cases of invasive breast cancer appear in women in this country. In a moment I will turn to the opportunities indicating that we can triumph in this area. The disease is so prevalent that unless we greatly expand our research efforts, 1 out of 11 American women living today are destined to die of this disease.

If the tragedy of breast cancer is not itself a compelling reason to increase Federal effort in this area, then let me remind you that of the total deaths from all forms of cancer in this country, breast cancer accounts for only 8 percent because the total is 500,000 if we include lung, prostate, colon, and so forth. This means that 1 out of 5 Americans living today will eventually die of cancer. This is an epidemic of very major proportions; yet, the total Federal effort in this area is minor.

At the same time, progress in this area both at the basic science and clinical levels has reached a very exciting crescendo. I am sure you read about this daily even in the newspapers. I do not have time to describe this progress in detail, but let me tell you some of the possibilities that it indicates.

We now know that at least 80 percent of cancer is due to external factors. It is not inherent in the human species to suffer a high risk of cancer, including breast cancer. The disease can be prevented, and clues are coming along with respect to diet, lifestyle, and hormones. We already know that 30 percent of lung cancer is due to cigarette smoking and, therefore, is an entirely preventable disease. Clues now emerging indicate that breast, colon, and prostate cancer, which together constitute about 60 percent of the remaining cancers, are also preventable. We are beginning to find the causes. We can complete that research and move on to preventive strategies.

The savings in terms of the health care bill in this country will in the area of lung cancer alone amount to $50 billion a year. That is the health care bill for lung cancer and related diseases. It is entirely preventable, but you must give us the wherewithal to complete the task of finding the cause and instituting prevention.

Very exciting progress is being made at the genetic level. We are finally really understanding the true nature of life in terms of genetic control and what has gone wrong in cancer cells. The Nobel Prize last year was given to Bishop and Varmas for this discovery. The NIH can take pride in that it provided total support for that research effort, and it is one of the great triumphs of cancer research.

Already, the clinical implications of those discoveries of oncogenes, suppressor genes, and growth factors have already reached the clinic, and I can tell you at our cancer center interdisciplinary programs are being mounted so that we can apply this new knowledge at the bedside, but we have no new resources. In fact, our cancer center, like others, is now trying to live with a 10-percent cutback in addition to the cost-of-living increase despite the fact that we have entirely new sets of knowledge.

You know about advances in biologic modifiers. You asked about the biotechnology industry, which we work closely with, in earlier questions. It depends upon us for basic research. In fact, the NIH can take credit that the most vital force in the new economy of this country is the biotechnology industry, and it owes its entire existence to NIH funding. So that is an investment which has paid off in enormous terms, and we are confident that an investment in the National Cancer Institute and the other Institutes of Health will revitalize our Nation intellectually and economically in the area of health care.

I could spend a good deal of time describing to you the exciting advances. At the same time, we are suffering these cutbacks. Other speakers have mentioned it, and it is true in the area of cancer research. We are not training the next generation. When we face the year 2000 we will not have a new generation of American scientists and biomedical investigators. If you go to my laboratory or cancer centers throughout the country, you will find that to an increasing extent that trained people are coming from foreign countries.

In our cancer center, 25 percent are from the Orient, 20 percent are from foreign countries, and that percentage continues to increase. Why? Because the salary slots are not available. For an individual who has gone through college and gotten a Ph.D. in biochemistry and enters our research laboratories, we provide them with a salary of $20,000 per year, and now when they apply for grants, even if they are brilliant and have novel ideas, the probability of that grant getting funded is less than 1 in 5, so they get letters approved but not funded, a highly discouraging atmosphere to hope to build a new generation of scientists and intellectual leaders in this country who will mount an approach in the biomedical area and in cancer.

This is a crisis situation. We are closing down laboratories. People are leaving the field and going elsewhere, and young people are not entering the field. What are we proposing, therefore? We fully back the proposal of the bypass budget to raise the current budget for the National Cancer Institute from $1.6 to $2.4 billion. As you know, that increase in $800 million is approximately the equivalent of one or two B-2 bombers. If we reach the budget of $2.4 billion, that is less than 1 percent of the defense budget.

If it is true that the defense budget can be trimmed 10 or more percent, would it make sense to divert at least a few percent of that to a major health problem in this country that kills 1 in 5 Americans and an area which will spark scientific training in minorities in all populations and enlist them in the general area of health care?

PREPARED STATEMENT

I would, therefore, urgently say that this is, by the way, our minimum budget, $2.4 million. It will restore some of the funding. It will prevent the closing of 5 and 10 cancer centers which has occurred during the past year. It will restore somewhat training funds. I think your committee must address at a larger issue the serious deterioration of science education in this country from the level of grade school on into postgraduate training. There is no doubt that we will lose as a Nation if we do not address that issue, and that extends to the area of cancer research and biomedical research in general.

I am sorry I ran overtime. It is my enthusiasm. Thank you.

[The statement follows:]

STATEMENT OF DR. I. BERNARD WEINSTEIN

Chairman Harkin and Members of the Subcommittee, my name is I. Bernard Weinstein. I am Director of the Comprehensive Cancer Center of Columbia University, President Elect of the American Association for Cancer Research (AACR), and a research investigator in the area of cancer causation and prevention.

I am delighted to have the opportunity to represent the AACR and present testimony on behalf of increased funding for the National Institutes of Health, specifically, the National Cancer Institute. The AACR is the professional society represents over 5,000 basic and clinical cancer researchers located at medical schools and universities, research institutes, and government laboratories across this country.

Without the support of this Subcommittee, the NIH would certainly have suffered dramatic cuts which were experienced by other Federal Agencies. On behalf of the AACR, as well as the cancer survivors, I wish to thank you for your support.

Let me briefly mention a few of the exciting advances made since the passage of the National Cancer Act in 1971:

Cancer Causation and Prevention: Epidemiologic and laboratory studies have provided evidence that at least 80% of human cancers are due to environmental (factors and, in principle are preventable. The identification cigarette smoking as the major cause of lung cancer (30% of all cancer deaths), and the subsequent institution of smoking cessation programs, has reduced its incidence. Evidence is accumulating hat dietary, hormonal and life-style factors play a role in breast, colon and prostate cancer. Thus, more intensive research could also lead to the prevention of these major forms of cancer.

Oncogenes and Suppressor Genes: Basic research studies supported almost entirely by NIH funds have led to the identification of oncogenes (cancer-causing genes) and of growth suppressor genes which inhibit tumor growth. Specific growth factors and the internal signals of cells that control cellular growth and differentiation have also been elucidated. These advances provide new insights into cancer causation, and specific tools for cancer diagnosis and staging. They also open the door to new and more rational strategies for cancer treatment. Indeed the 1989 Noble Prize was awarded to Drs. Micheal Bishop and Harold Varmas for the discovery of oncogenes in the mid 1970's.

Biological Response Modifiers and Biotechnology: Fundamental advances in immunology and molecular biology, coupled with biotechnology, have also led to novel and exciting approaches to cancer treatment. These include the spectacular studies by Steven Rosenberg using lymphocyte-activated killer cells and interleukin-2 therapy, the development of interferon and colony-stimulating factors and of antibodies that can be specifically targeted to cancer cells.

Indeed the research supported by the NIH has spawned the entire biotechnology industry - a major new biomedical and economic force in this country and abroad. At a time when we are concerned about the vitality of this Nation's industry and economy, we can take pride in this example of the spin-off generated by the NIH research program.

Adjuvant Therapy and Chemotherapy: During the past 20 years major advances have been made in the treatment of breast cancer, a disease that strikes one out of every eleven women. The disfiguring radical mastectomy procedure has been replace by lumpectomy followed by radiation therapy or chemotherapy. Advances are also being made in the treatment of more advanced stages of this disease. At the same time the institution of mammography programs has led to the detection of breast tumors at an early stage when treatment is more effective.

Just within the past year results have been published indicating that adjuvant therapy (with a combination of drugs) of colon cancer, a disease which thus far has been quite resistant to chemotherapy, holds great promise.

These are just a few of the exciting advances in therapy. They indicate the opportunities for even greater advances if adequate resources for drug development and clinical trials are made available.

This year the Ad Hoc Group for Medical Research has recommended an overall NIH budget of approximately $9.2 billion. We support this proposal as an absolute minimum level of funding which the Congress should accept. We are on the brink of major biotechnological breakthroughs. Our basic science efforts are paying off. A long-range investment must be made in support of the National Institutes of Health.

The National Cancer Advisory Board has transmitted to the President the FY 1991 By-Pass Budget, a needs budget, of approximately $2.4 billion. This is the level of funding which the cancer research community feels is essential to support the research opportunities. The President's FY 1991 Budget Request, however, falls $716 million short of this recommended level.

The fundamental structure of our National Cancer Program is now being threatened. **For instance, after the passage of the National Cancer Act, 60% of all approved meritorious research grants at the NCI were funded. Under the FY 1991 President's Budget it is estimated that only 27% of the approved grants will be funded.** In addition the President's Budget would subject our cancer program to the following reductions:

- The overall number of grants supported by the NCI would be reduced.
- Budget cuts in the form of **downward negotiations** of 20% and 4% would be required on competing and noncompeting grants, respectively.
- No new growth in the cancer centers and the cancer prevention and control programs.

Research training is paramount in our efforts to solve the cancer problem. Without replenishing the pool of researchers we will suffer major interruptions in our ability to advance medical research. The National Cancer Advisory Board has recommended that the appropriate level of funding would be to support 1,600 research trainees; the President's budget would only support approximately 1,400 trainees. It is critical that we strengthen the infrastructure from which we demand results.

If however the By-Pass-Budget was fully funded the NCI could provide for the following essential of support:

- Full funding of a 50% award rate for approved competing research grants;
- Full funding for non-competing research grants;
- Full funding to the existing cancer centers, restoration of funds to 10 centers phased out in 1989 and 1990 and funding to 5 new cancer centers;
- Expansion of application of new advances in molecular biology to cancer prevention and treatment;
- Expansion of the number of clinical trials;
- Increase funding for studies on cancer in minority and over-65 populations;
- Expansion of cancer prevention and control programs;
- Expansion of cancer information dissemination activities; and
- Expansion of the biological modifiers approach to cancer treatment.

Another important aspect of the infrastructure which has been allowed to deteriorate is our research facilities. Many of our cancer research laboratories have antiquated physical facilities. These are the facilities which are expected to produce state-of-the art medical breakthroughs, yet we have not had sufficient funding within the NCI to support renovations, or new construction projects for many years.

Fewer real dollars are being directed into cancer research and high priority areas of research are under-funded. If Congress does not commit the needed dollars to the National Cancer Institute, a sad reality is that treatments and cures that might be possible in five or ten years will not be available. Each year approximately 500,000 Americans die of cancer. This means that one in 5 Americans living today will die of cancer unless we reverse this trend.

Cancer scientists have an urgent need to work with the Congress to establish a long range budget for biomedical research. Our perspective must be shifted from year by year budget crisis to long range planning. We must assure that the NIH maintains its preeminent role in providing the new knowledge that will lead to the prevention and/or cure of major diseases, like cancer, that threaten all Americans. I am certain that we can count on the support of the Subcommittee to demonstrate the same level of dedication and commitment which has been evidenced in the past. If myself or my colleagues can be of assistance to any Members of the Subcommittee please do not hesitate to contact us.

Thank you for your time. As always it has been a privilege for the AACR to present testimony before the Labor/HHS/Education Subcommittee. I would be happy to answer any questions.

Senator **Bumpers**. Dr. Weinstein, if you will arrange to get me elected king in this country, we will get all of this done. We will stop the insane priorities that we have been off on in the past 10 years. It would take about 1.5 B-2 bombers to address your problem, and I can tell you I am sure going to try to do just that.

I do not care how many tanks and planes and guns we have. They do not amount to a tinker's damn if we let a generation go uneducated and cannot house our people, provide health care, or do the kinds of research that gives my grandson some half decent prospect for a healthy future.

You are preaching to the saved, but I loved every minute of it.

Dr. **Weinstein**. Thank you. I appreciate your full support.

Senator **Bumpers**. If I really said what I want, we would be here until about 5 p.m. tonight.

Senator **Specter** [presiding]. I did not mind listening to your additional comments, Dr. Weinstein, but not to Senator Bumpers. I have heard enough of him. [Laughter.]

I agree with him.

STATEMENT OF RICHARD G. LYNCH, M.D., UNIVERSITY OF IOWA COLLEGE OF MEDICINE, ON BEHALF OF THE AMERICAN ASSOCIATION OF IMMUNOLOGISTS

ACCOMPANIED BY DR. THOMAS WALDSCHMIDT, UNIVERSITY OF IOWA COLLEGE OF MEDICINE

Senator **Bumpers**. I would like to call on Dr. Richard Lynch, University of Iowa College of Medicine, for the American Association of Immunologists.

Please proceed.

Dr. **Lynch**. Mr. Chairman, thank you for the opportunity to address this subcommittee. My name is Richard Lynch. I am professor of pathology and head of the Department of Pathology at the University of Iowa. I represent more than 5,000 members of the American Association of Immunologists. You have my written statement, and what I would like to do in a few moments that are available is summarize and highlight some of the points in that written document.

Senator **Specter**. That would be fine. All statements are made a part of the record, so just proceed.

Dr. **Lynch**. I am here to specifically request that funds be appropriated to the National Institutes of Health so that in fiscal year 1990 the number of new and competing RO-1 grants be restored to 6,000 from the current projection of 4,600.

In 1987 the NIH funded 6,400 RO-1 grants. In 1989 that dropped to 5,300 grants, and it is projected that in 1990 it will drop again to 4,600 grants.

Now why are we making this request? We are making this request because biomedical science in this country is in a crisis. The crisis is manifested by a progressive erosion of the quality of science as well as an erosion of the number of individual junior scientists entering the field of biomedical research. Because of the current funding situation, talented, imaginative, highly qualified scientists cannot get research grants. They are leaving science. The students that they would have trained are not entering science programs.

I have with me Dr. Thomas Waldschmidt, an immunologist and a junior faculty member at the College of Medicine at the University of Iowa. Dr. Waldschmidt represents the next generation of immunologists.

We have heard this morning some very interesting and moving testimony about the important health problems that need to be solved by continued basic research. Why do we need the next generation of immunologists? We need it to continue the process of discovery, discovery that has led to vaccines that have eradicated diseases like polio, have eradicated diseases like the RH problem of newborns, that have protected now our national blood supplies so now the AIDS virus is no longer transmitted as a complication of blood transfusion. Time does not permit recitation of all the accomplishments that have come from basic research in immunology.

We have heard about a number of important diseases. Earlier this morning we heard about juvenile diabetes. That is an immunological disease, and the cure and prevention of that is going to come from basic immunology. We need this next generation of immunologists to staff the faculties of universities, research institutes, positions in the private sector and to train future scientists for industry to provide the sound leadership and counsel for our national health programs.

Last week the University of Iowa was listed in the U.S. News and World Report in a survey of the top medical schools in the country. We were very proud of that listing, and we have been able to achieve this level of quality because we have been able to successfully attract to our faculty junior faculty members who come from the best training programs in the United States.

The current research funding situation is a disincentive to many of these individuals. They are not selecting careers in research, and this is going to create a problem for us down the road. There are not enough scientists in biomedical research in the pipeline. So I am very concerned about the dearth of young scientists in the pipeline, and the current situation in funding is making this worse.

PREPARED STATEMENT

Mr. Chairman, I want to thank you for the opportunity to present our case to the committee.

Senator SPECTER. Thank you very much, Dr. Lynch. We appreciate your testimony, and we will give very careful consideration to what you have had to say.

[The statement follows:]

STATEMENT OF RICHARD G. LYNCH

Mr. Chairman, Ladies and Gentlemen:

Thank you for the opportunity to testify before the Senate Appropriations Subcommittee on Labor, HHS, Education.

I represent over 5,000 members of the American Association of Immunologists. Both basic scientists and clinicians in our society conduct research on major immunologic diseases, regulation of the immune system in health and disease, transplantation and tumor biology, and organ specific disorders such as diabetes and inflammatory diseases of the skin, gastrointestinal tract and eye.

I am appearing before you to request additional new funds for the NIH, not just for immunology, but for all areas of research. To be specific, we are requesting that the number of new and competing R01 grants approved and funded be restored to 6,000 from the 4,600 projected for FY 1990. It is essential that the reduction in the funding of competing grants be reversed if we are to maintain the momentum in our efforts to conquer disease. The increase in R01s means that the total number of funded grants would be 21,344, an increase of 1028 over FY 1990. We estimate it would cost $386 million more to achieve that goal.

Why do we feel compelled to ask this in the era of budget reduction and pressing domestic programs also requiring funds? Because science in the United States is in crisis. First, as has been alluded to, there is a dearth of scientists in the pipeline in immunology and other fields. We cannot fund young people, and by that I mean young MDs and PhDs who are roughly in the 25-35 year old bracket. They cannot get research grants which have been cut, in number and size, and cannot be funded by training grants, which have suffered even deeper cuts. There is not enough money to go around, and these talented young people know this. They are leaving science for other careers, or not entering it in the first place.

Secondly, there are new areas of research in immunology that are just not getting funded at all. For example, more funds are required to analyze how chronic environmental toxins affect the immune system of humans and animals. We need to understand the impact of the thinning ozone layer and increased UV light on skin diseases such as malignant melanoma, and we must design much more efficacious vaccines against infections such as flu and pneumonia, which pose major health threats to the very young, the elderly, and immunologically impaired. Quite frankly, the existing money does not cover current needs and will never fund the new, emerging areas of concern.

Mr. Chairman, thank you for the opportunity to present our case to your committee. We urge you to consider this request which will benefit the present and future generations of scientists and will lead to a healthier America.

THE CONTRIBUTIONS OF BASIC IMMUNOLOGY RESEARCH DURING THE PAST DECADE

Basic research in Immunology has made important and often outstanding contributions toward the treatment and prevention of serious human diseases, toward improving the quality of life for millions of Americans, and in lessening, or at least ameliorating, the escalating costs of health care.

No one could have predicted, even 10 yars ago, the impact a disease such as AIDS could have on our society, nor could we have anticipated the burden that has been placed on our acute and chronic care hospitals. Despite this terrible epidemic, the investment of the previous decade in basic research on lymphocytes, their surface markers and their functions, has paid off handsomely -- permitting a rapid understanding of the pathogenesis of AIDS, and development of strategies at both the biomedical and social levels to limit the spread of this disease. Although a cure for AIDS remains elusive, we are far closer to achieving one because of the platform of fundamental information that was, and is currently being accumulated by basic immunology research workers.

Of equal importance to modern biology and medicine has been the identification and description of lymphokines and other cytokines, growth and differentiation factors that implement and regulate the immune response. Clinical benefits are already emerging from this work -- growth factors are being used to expand small populations of bone marrow cells for use in bone marrow transplantation in man; antibodies have been engineered that suppress lymphokines that cause excessive inflammation in autoimmune and other diseases.

The large investment in basic immunologic approaches toward the development of immunopharmacologic agents has also borne fruit: patients are now receiving chemotherapeutic drugs that are targeted to specific tissues and even to malignant tumor cells. By this simple, elegant approach much larger doses of drugs can be delivered to tumors with much less toxic side effects for the patient, and a better quality of life.

Basic research has generated monoclonal antibodies to lymphocyte markers which have then been conjugated with toxins. Using this strategy, a new and potentially revolutionary approach to immune suppression in human organ transplantation is on the horizon. Each year, thousands of patients in the United States undergo organ transplants. This new therapeutic approach is expected to improve dramatically the success of clinical transplants -- to the significant benefit of recipient patients. Moreover, it is likely to reduce in a major way the aggregate costs of transplantation -- in terms of accelerating the rate at which transplanted patients may return to their jobs, and in reducing costs of hospitalization and chronic care.

Advances in our understanding of basic molecular immunology have been particularly exciting. Only recently have we learned that cells receive and send signals through cell cytokines and their surface receptors. Because of this new knowledge, we now understand how the AIDS virus binds to lymphocytes -- offering an approach to preventing infection of the cell, by blocking the receptor. Much has been learned about the molecules of the major histocompatibility complex (HLA) which are central to many serious autoimmune diseases, such as lupus erythematosis, diabetes, and rheumatoid arthritis. Much remains to be learned concerning the molecular means by which these genes and molecules participate in the expression of these diseases. Already, basic research on the allelic forms of HLA genes gives hope that individuals at risk for developing autoimmune and inflammatory diseases may be identified prospectively.

At this critical time, a greater investment in basic immunologic research is needed not only to exploit the opportunities implicit in the topics mentioned above, but to meet the extraordinary challenges which our society faces now and in the near future. Deterioration in our environment is generally recognized as a major problem that will progressively affect the quality of our work and our lives. It may not be readily apparent that as our environment is altered, there is and will be a major impact on the immune systems of humans and other animals that must live in this abnormal environment. Evidence suggests that chronic exposure to environmental toxins in fresh and salt waters, such as our coastal reefs and estuaries, impairs the immune systems of fish and other aquatic creatures, leading to death from infection and tumors. The economic impact alone of this outcome is and will be enormous. In addition, progressive thinning of the ozone layer of the earth's atmosphere due to accumulation of air pollutants is already taking its toll on our species. The ultraviolet light that can penetrate through an atmosphere deficient in ozone directly impairs the skin immune system of human beings, leading to the frightening increase in the incidence of skin cancer, especially in areas of the USA where sun exposure is high. Basic research on the impact of environmental toxins and pollution on the immune system has barely begun and is clearly underfunded -- even though the threat is immediate.

Environmental hazards are but one of several challenges that face the health of our citizens. The community of basic immunologic scientists represented by The American Association of Immunologists is prepared to accept these and other challenges. However, even as these challenges appear, the number of young people opting for a career in biomedical science is dropping. The perception (and the reality) is that even established, productive investigators experience great difficulties in competing successfully for grant funds to support research. The funding crisis is particularly great for young investigators. In order for our field to move ahead in meeting the formidable challenges we face, the overall level of grant support from NIH must be increased; this is especially true for young investigators. Only when we can assure our bright and talented young people that a career in basic research is scientifically rewarding and will be fully supported by our government and society can we expect to solve the important biomedical problems we face in the immediate and distant future.

We urgently request that the Congress restore to the FY 1991 budget funds sufficient to insure that the number of new and competing R01 grants which are approved and funded by the NIH will be 6,000. This number would mean that the total number of funded grants would be 21,344, an increase of 1028 over FY 1990, and that the increase for this in the NIH budget would be approximately $386 million for FY 1991.

The American Association of Immunologists is comprised of more that 5,000 members. Its roster includes basic scientists, clinical scientists, and clinicians dedicated to research on major immunologic diseases, regulation of the immune system in health and disease, transplantation of organs and tissues, immune responses to tumors, organ-specific autoimmune disorders such as diabetes, and inflammatory diseases of the skin, the eye, the joints, and the gastrointestinal tract. Although funding for the aggregate research effort of immunologists comes from many different sources, the major source of funding is the National Institutes of Health, especially the National Institute of Allergy and Infectious Diseases. This summary, proposal and request for increased funding for basic immunologic research through NIH is made on behalf of the AAI membership by its Public Affairs Committee, and the President of AAI.

Senator SPECTER. Do you want to add a word or two?

STATEMENT OF DR. THOMAS WALDSCHMIDT

Dr. WALDSCHMIDT. Several speakers have talked about the young scientists who are having problems getting funding.

Senator SPECTER. Would you identify yourself, please?

Dr. WALDSCHMIDT. I am Dr. Tom Waldschmidt from the University of Iowa, assistant professor. I represent those type of investigators. I have spent 11 years since college training to be a scientist. I have been an assistant professor for 1½ years, and I am in the process now of writing my fourth NIH grant application. They have all done very well, but they have not hit the level of funding simply because there is not enough money. It is frustrating and, of course, it makes me consider my future.

Senator SPECTER. Thank you very much. We face very tight constraints, and we hear you. It is a repetitive and important theme, and we will consider it very carefully. Thank you.

STATEMENT OF MARILYN PRICE SPIVACK, NATIONAL HEAD INJURY FOUNDATION

Senator SPECTER. Next, Mr. Charles Haynes, chairman of the National Head Injury Foundation.

Ms. Spivack, I do not know why we have you listed incorrectly, but go ahead.

Ms. SPIVACK. I want to thank you, and I want to introduce two members who will not speak unless you want to ask them some questions which they would be delighted to answer: Barbara Thorpe from Maryland, who is a survivor of head injury; and Robert DeMichaelis from Maryland, who is a survivor of head injury.

I am delighted to have them here with us. Barbara and Robert represent the survivors of head injury who we have in the past referred to as the walking wounded, the silently injured, because their disabilities are not obvious at first response.

My name is Marilyn Spivack, and I am the founder and, up until March 1, the president and CEO of the National Head Injury Foundation. In 1975, Senator, my daughter was severely brain damaged in an auto accident. A year later, my son was killed in a motorcycle accident. Two years after that my husband died from a bullet wound in his head. I have lost family and dear friends to Alzheimer's, cancer, heart disease, and, very recently, AIDS. My husband works in the AIDS movement.

I am very familiar with the constraints that you and this committee have to face. We have been coming to you for 7 years. You have done a great deal for us. You have done a great deal for us through your language, not through appropriations. I will say I recognize that this is the first year that the Congress of this country has designated $15 million. I was told that was a lot of money, and I appreciate the $15 million. Our constituency appreciates $15 million.

As you notice, I am leaving my testimony aside. Let us note that head injury takes someone every 15 seconds; someone is dying every 5 minutes; and somebody is going to be left like my daughter. I could not bring my daughter here because she is too severely injured to manage this trip, and the complexity of the trip is too great for her.

Senator Specter. How old is she?

Ms. Spivack. She is 30. She was 15 when she was injured. Robert is the love of her life.

My time is up. You have the appropriations that we would like to see in various institutions, various agencies throughout the Health and Human Services and Department of Education. What I specifically want to ask you, Senator, is if you would with your committee urge the action needed on the interagency task force report.

You know that Senator Harkin held a hearing a couple of years ago for us. You know that your language made an interagency head injury task force happen. You know that that task force was sent up to the Department of Health and Human Services as Dr. Bowen was leaving. That task force report contains six major recommendations and a national strategy. That report is dying. It is a report that needs life put back into it. We need you to promote that.

Senator Specter. We will do what we can, Ms. Spivack. We very much appreciate your coming in.

Ms. Spivack. Thank you.

Senator Specter. Thank you.

STATEMENT OF JUNE GLASER, THE MEDICAL LIBRARY ASSOCIATION AND THE ASSOCIATION OF ACADEMIC HEALTH SCIENCES LIBRARY DIRECTORS

Senator Specter. Ms. June Glaser, Medical Library Association and Association of Academic Health Science Library Directors.

Thank you very much for joining us. We have your statement, and it will be a part of the record. You may proceed.

Ms. Glaser. I am June Glaser, librarian of the Eastman Dental Center and chairman of the Governmental Relations Committee of the Medical Library Association. Thank you for giving me the opportunity to speak in support of adequate fiscal year 1991 appropriations for the National Library of Medicine. NLA is a professional organization which represents over 5,000 individuals and institutions involved in management and the dissemination of biomedical information in support of patient care, education, and research.

The President's budget request for NLM for fiscal year 1991 is $89.9 million. MLA firmly believes, however, that funding at the level of $121.5 million is required. Of highest priority to MLA are the outreach initiatives recommended in the NLM 1989 planning panel report improving health professionals' access to information, challenges, and opportunity for the National Library of Medicine.

Under the present fiscal year 1991 budget, $3.9 million is budgeted for outreach, far below the $35.5 million recommended to meet the second-year goals of this report. Funds are needed for the five outreach initiatives.

The regional medical library network: For more than 20 years the RML network has served as the primary outreach vehicle for NLM through its seven regional networks. It has linked all types and sizes of health sciences library. NLM is now working to expand this network to include the Nation's health professionals, particularly those in the rural and underserved areas.

Integrated academic information systems: NLM provides assistance to medical centers, health and science institutions and organizations for planning and developing institutionwide computer networks. Increased funding is needed to assure the continuation of this program.

NLM also offers other grants to small- and medium-size hospital libraries and information system grants to larger hospitals and academic health centers. These grants are aimed at improving the information infrastructure through computer and communication technologies.

The training centers and awards: There is a critical need for skilled health information scientists who build and manage the next generation of information systems. NLM needs to increase the number of medical informatic training centers, individual awards for research training, career development, and demonstration grants.

Last, the products and services of NLM: NLM has been responsive to the needs of the health professionals and the vast network of libraries. Additional funds are needed to continue developing, improving, and promoting its many products and services.

PREPARED STATEMENT

The National Library of Medicine plays an important role in educating health professionals and researchers throughout the world. This important mission requires that NLM and our Nation's medical libraries stay on the cutting edge of technological advances in the information sciences field and warrants adequate funding.

Thank you for the opportunity to present this testimony in this important area of Government funding.

Senator **Specter**. Thank you very much, Ms. Glaser. We appreciate your being here. and we will carefully consider your testimony.

[The statement follows:]

STATEMENT OF JUNE GLASER

The Medical Library Association (MLA) welcomes the opportunity to speak in support of adequate FY 1991 appropriations for the National Library of Medicine (NLM). MLA is a professional organization which represents approximately 5,000 individuals and institutions involved in the management and dissemination of biomedical information in support of patient care, education and research. One of MLA's goals is to ensure that biomedical information is made available to health sciences libraries and accessible to health care professionals, scientists, students and patients throughout the nation. MLA members are leaders in developing and applying new health sciences information delivery systems, fostering educational and research programs, and encouraging an enhanced public awareness of health care issues. This leadership is nowhere more visible than in the programs and services of the NLM.

The President's budget request for the NLM for FY 1991 is $89.916 million. However, MLA firmly believes that funding at the level of $121.5 million is required in order for the NLM to fulfill its outreach mission and meet its goals and priorities for the coming year. Specifics of our recommendations are highlighted below.

OUTREACH INITIATIVES

Of highest priority to MLA are the outreach initiatives which were recommended in the NLM Planning Panel report, "Improving Health Professionals' Access to Information: Challenges and Opportunities for the National Library of Medicine" issued in June 1989. The panel, chaired by Dr. Michael DeBakey, identified four major challenges and opportunities for NLM, recommended specific actions, and spelled out the financial and personnel resource requirements necessary to accomplish NLM's goal to develop an outreach program.

Under the President's FY 1991 budget, $3.911 million is budgeted for Outreach, far below the $35.5 million recommended in the DeBakey report to meet the 1991 goals of this important effort. The $35.5 million figure includes funds earmarked to:

Enhance the Regional Medical Library Network ($6 million). For more than 20 years the RML program has served as the primary outreach vehicle for the National Library of Medicine. Through its seven regional networks, the RMLs have linked together all types and sizes of health sciences libraries and information centers through cooperative arrangements and interlibrary loan and resource sharing activities. In addition, the RMLs have served as training centers and promoters of the many products and services of the NLM. NLM is now working with members of the RML network to improve delivery of NLM's services to the nation's health professionals, particularly those in the rural and underserved areas. However, inadequate funding will prohibit the RMLs from providing proactive, electronically sophisticated information services to those professionals who presently have little or no access to health sciences or public libraries. The MLA, therefore, supports funding of $6 million to enhance the RML network.

Expand Integrated Academic Information Management Systems (IAIMS) ($7 million). NLM provides grant assistance to medical centers, health science institutions and organizations for planning and developing projects leading to the implementation of IAIMS. IAIMS are institution-wide computer networks that link related library systems with individual and institutional databases and information files, within and external to the institutions, for patient care, research, education and administration. Interest in the IAIMS program is extensive, reflecting the critical need to provide better access to the scholarly record and to the vast array of medical databases. IAIMS grants have provided support to a total of 14 institutions for planning (Phase I) and/or development (Phase II) of institution-wide systems. In FY 1989, two awards were made for Phase III, full implementation of prototypes of these integrated systems. Increased funding is needed for IAIMS to assist a larger number of institutions that are planning for integrated information services and to insure sufficient models to accommodate the diversity of IAIMS sites. MLA supports a funding level of $7 million to insure the continuation of the IAIMS grants program for information systems in medical schools.

Assist Local Institutions by Increasing Resource Grants ($3 million). Resource grants assist public and private, non-profit health science libraries to establish, expand and improve library resources and information services to health personnel engaged in education, research and patient care. The Resource Grant Program has changed focus to concentrate upon utilizing computer and communications technology to gain access to information resources and services. The program now offers access grants to small and medium-sized hospital libraries, and information systems grants to larger hospitals and academic health centers. The latter type fosters networking, linkages, connectivity, and integration -- all toward improving the information infrastructure through computer and communication technologies. MLA supports $3 million for NLM's Resource Grant Program.

Increase Number of Training Centers and Individual Awards ($12 million). An outcome of the IAIMS program grants is recognition of the critical need for a cadre of skilled health information scientists to build and manage the next generation of information systems. Although NLM has supported medical informatics training at the predoctoral and postdoctoral levels, the scale and range of this program is simply not great enough to meet present and future needs. Even the major university medical centers that have concentrated their resources on planning for institution-wide information services have found that locating and recruiting senior professionals with this kind of education and training is their greatest obstacle. NLM should substantially increase the number of Medical Informatics training centers, individual awards for research training and career development, and demonstration grants. MLA supports $12 million in funding in this area.

Publicize and Promote the Use of NLM's Current Products and Services ($7.5 million). NLM continues to develop and improve its many products and services, including GRATEFUL-MED, DOCLINE, MEDLINE, and AIDSLINE. Database access is of paramount importance to the health sciences professional community. NLM has been responsive to the information needs of the health professionals and the vast network of libraries. However, in order to continue to expand and enhance its programs and services and to be able to publicize what is available, additional funding is needed. MLA supports $7.5 million in funding for this area of public outreach.

MLA recognizes the fiscal constraints facing all federal agencies and the need for prudent use of our national resources. We recognize that the Congress may be unable to fully fund the second year of the NLM's important and ambitious outreach efforts. However, MLA also recognizes the vital role the National Library of Medicine plays in educating health professionals and researchers throughout the world so that precious health care and human resources are not wasted. This important mission requires that NLM and our nation's medical libraries stay on the "cutting edge" of technological advances in the information sciences field, and warrants a significant infusion of new funds in order to achieve this goal. Thank you for the opportunity to present testimony on this important area of government funding.

STATEMENT OF REV. WILLIAM L. GEORGE, SPECIAL ASSISTANT TO THE PRESIDENT, MEDICAL CENTER, GEORGETOWN UNIVERSITY

ACCOMPANIED BY MARY S. ALBERT, GEORGETOWN UNIVERSITY

Senator SPECTER. I would like now to call on Reverend George and Ms. Mary S. Albert, Georgetown University.

Reverend GEORGE. Good afternoon, Mr. Chairman. I am Father William George, special assistant to the president of Georgetown. With me is Mary Albert from our medical center. Father Collins, my mentor, asked me to pinch hit for him, so that is why I am here.

Senator SPECTER. I appreciate your being here. Thank you.

Reverend GEORGE. We would just like to thank you for the support over the years of the HEAL Program. It has enabled our university to hold its medical tuition constant for 3 years, but what it really does is help us have sort of blind admissions where you do not have to look at whether the student can afford to go to medical school or not. You can just take whoever you think is qualified and talented enough. So we are grateful for that and just ask you to continue to support it.

We also were one of the initial groups funded under the National Library of Medicines IAIMS Program. We would like to support that, and we are negotiating a contract with our bioethics center. Ethics is a good thing to discuss, so we are hoping to follow through with that.

PREPARED STATEMENT

Finally, we are planning a children's facility, and it will be doing a lot of clinical research on maternal and infant care. We are working with the National Institute of Child Health and Human Development on developing a program for that, and we will keep you informed on that one as well.

We really wanted to say thank you on behalf of our new president, Father O'Donovan, and do not bet against the Hoyas next year.

Senator SPECTER. Thank you very much. We very much appreciate your being here. Thank you.

[The statement follows:]

Statement of Rev. William L. George

Mr. Chairman: I am Reverend Wm. L. George, S.J., Special Assistant to the President of Georgetown University. I am accompanied by Mary S. Albert, Director of Government Affairs for our Medical Center. We are delighted to be here this morning to testify before you on the FY 1991 Appropriations.

Our testimony is brief:

First, we would like to thank the Committee for the Health Education Assistance Loan (HEAL) program. Our medical school, by rigorous management, has been able to keep tuition constant for the past three years. At $22,500, we are no longer the most expensive medical school in the United States, a title we held with little relish for many years. Nevertheless, it costs our students about $30,000 each year to attend our school, and many of our students are dependent on the HEAL program. (They borrowed over $4 million this academic year.) The HEAL program enables us to have a financially blind admissions policy—a policy we very much want to continue since we do not wish to become a school which only the very affluent can attend. We appreciate your support of this program over the years.

Second, we wish to tell you how pleased we are with the National Library of Medicine's Integrated Academic Information Management Systems (IAIMS) program. Our library was one of the initial group funded in this program, and we recently received a further grant. The development of this program has had a dramatic impact on our Medical Center, our affiliated institutions, and, increasingly, our physician population outside Georgetown. Also, we are presently negotiating a contract between the NLM and our Bioethics Center, which the Committee has supported for years. We will keep you fully informed.

Third, Georgetown is now planning the construction of a major addition to our University Hospital—a four story Perinatal Center. This addition will modernize our present patient facility and will contain a research floor that will permit clinical research on maternal/infant care. We hope to work even more closely with the National Institute of Child Health and Human Development as our program develops, and we will be coming to you later to suggest ways in which this might be achieved.

Our testimony is brief this morning, and essentially is a thank you for supporting programs that have geen very important to our Medical Center.

STATEMENT OF CAROLYN ZOLLAR, GENERAL COUNSEL, NATIONAL ASSOCIATION OF REHABILITATION FACILITIES, ON BEHALF OF THE NATIONAL REHABILITATION CAUCUS

Senator SPECTER. Now I would like to call on Ms. Carolyn Zollar, general counsel, National Association of Rehabilitation Facilities.

Ms. ZOLLAR. Thank you, Senator. My name is Carolyn Zollar. I am the general counsel for the National Association of Rehabilitation Facilities. I am appearing today on behalf of the National Rehabilitation Caucus, a coalition of health care consumers, professional and institutional and community-based providers. We want to express our appreciation for the opportunity to appear and ask, of course, that the full statement be included in the record.

The purpose of our testimony is to urge the subcommittee to make appropriations for funding of several allied health education initiatives authorized under title 7 of the Public Health Service Act. They authorize funds for program expansion, faculty development, and student loan repayment. The caucus would also like to thank this subcommittee for the support provided for this initiative during last year's appropriations process. The funding that was approved for fiscal year 1990 resulted from the efforts and commitment of this subcommittee, and our members are aware and deeply grateful.

The need remains, however. Health care providers face severe shortages of allied health professionals. Hospitals, rehabilitation facilities, schools, nursing homes, home health agencies, and others simply cannot recruit enough qualified personnel to provide services. The shortage is particularly acute with respect to rehabilitation professionals such as occupational physical therapists and others whose skills and services are important in serving the elderly and persons with disabilities.

Studies have documented this problem. The 1988 Institute of Medicine study notes that absent concerted intervention to train new personnel, these shortages will intensify, with the most serious shortages by the year 2000 being the occupational and physical therapy professions. The American Hospital Association's most recent study of 7,000 hospitals showed vacancy rates of more than 16 percent for physical therapists, 15 percent for occupational therapists, with State-specific data showing a 20-percent vacancy rate in Iowa and 15 percent in Pennsylvania for therapists.

In response to these shortages, facilities have been forced to reduce services, close beds or units, and divert patients to other facilities.

The health care community is trying to meet the problem, but Federal support is essential. The most immediate need is to expand program and faculty resources. Education program directors say the most important factor inhibiting expansion is availability and recruitment of qualified faculty members. Full funding of the title 7 allied health education initiative is critically important. We strongly urge the subcommittee to fund sections 751, 796, and 797 at the total authorized level of $6 million.

While $750,000 was appropriated for section 796 last year, the Bureau of Health Professions received over 2,000 inquiries once the availability of funds was published and ultimately received over 122 grant proposals before the application deadline. More institutions were interested in submitting proposals that were hampered by the short timeframe available. We believe this is compelling evidence of the need.

PREPARED STATEMENT

In some, although the three title 7 initiatives are modest when measured against the need, they represent an important step toward addressing the problem and are vitally important to meet the health care needs of the elderly and persons with disabilities.

Again, we thank you for this opportunity to testify today.

Senator SPECTER. Thank you very much for coming in. We appreciate it, and your full statement will be made a part of the record.

Ms. ZOLLAR. Thank you.

[The statement follows:]

STATEMENT OF CAROLYN ZOLLAR

MR. CHAIRMAN AND MEMBERS OF THE SUBCOMMITTEE:

ON BEHALF OF THE NATIONAL REHABILITATION CAUCUS, A COALITION COMPRISED OF ORGANIZATIONS REPRESENTING HEALTH CARE CONSUMERS, HEALTH PROFESSIONALS, AND INSTITUTIONAL AND COMMUNITY-BASED SERVICE PROVIDERS, I WANT TO EXPRESS OUR APPRECIATION FOR THE OPPORTUNITY TO APPEAR BEFORE YOU TODAY.

THE PURPOSE OF OUR TESTIMONY THIS MORNING IS TO URGE THE SUBCOMMITTEE TO SUPPORT APPROPRIATIONS NECESSARY FOR THE FUNDING OF SEVERAL ALLIED HEALTH EDUCATION AND TRAINING INITIATIVES AUTHORIZED UNDER TITLE VII OF THE PUBLIC HEALTH SERVICE ACT. THE CAUCUS WOULD ALSO LIKE TO THANK YOU, MR. CHAIRMAN, AND OTHER MEMBERS OF THIS SUBCOMMITTEE FOR THE SUPPORT YOU PROVIDED FOR THESE INITIATIVES DURING LAST YEAR'S APPROPRIATIONS PROCESS. THE FUNDING THAT WAS APPROVED FOR FISCAL YEAR 1990 RESULTED FROM THE EFFORTS AND COMMITMENT OF THIS SUBCOMMITTEE, AND OUR MEMBERS ARE AWARE OF THAT AND DEEPLY GRATEFUL.

AS YOU KNOW, MR.CHAIRMAN, HEALTH CARE PROVIDERS THROUGHOUT THE COUNTRY CONTINUE TO FACE SEVERE SHORTAGES OF ALLIED HEALTH PROFESSIONALS. HOSPITALS, NURSING HOMES, HOME HEALTH AGENCIES, REHABILITATION FACILITIES, AND OTHER SERVICE PROVIDERS ARE UNABLE TO RECRUIT SUFFICIENT NUMBERS OF QUALIFIED PERSONNEL TO PROVIDE ESSENTIAL SERVICES. THIS MANPOWER DEFICIT IS PARTICULARLY ACUTE WITH RESPECT TO REHABILITIATION PROFESSIONALS SUCH AS OCCUPATIONAL THERAPISTS, PHYSICAL THERAPISTS, SPEECH-LANGUAGE PATHOLOGISTS AND OTHERS WHOSE SKILLS AND SERVICES ARE SO IMPORTANT IN THE PROVISION OF CARE TO THE ELDERLY, THE CHRONICALLY ILL, CHILDREN WITH DISABILITIES, AND OTHERS.

THESE PERSONNEL SHORTAGES RESULT FROM A COMBINATION OF FACTORS, INCLUDING A SURGE IN DEMAND FOR SERVICES FROM A

POPULATION IN WHICH MORE INDIVIDUALS SURVIVE INTO OLD AGE, OFTEN WITH CHRONIC CONDITIONS OR MULTIPLE DISABILITIES. MEDICAL AND TECHNOLOGICAL ADVANCEMENTS HAVE ALSO INCREASED THE FREQUENCY OF SURVIVAL FROM ACCIDENTAL TRAUMA OR SEVERELY DISABLING CONDITIONS PRESENT AT BIRTH, HEIGHTENING THE DEMAND FOR REHABILITATION SERVICES WHICH ENHANCE FUNCTIONAL INDEPENDENCE AND QUALITY OF LIFE.

THE AMERICAN HOSPITAL ASSOCIATION'S MOST RECENTLY COMPLETED SURVEY OF 7,000 HOSPITALS SHOWED VACANCY RATES NATIONWIDE OF MORE THAN 16 PERCENT FOR PHYSICAL THERAPISTS AND 15 PERCENT FOR OCCUPATIONAL THERAPISTS, WITH STATE-SPECIFIC DATA INDICATING VACANCY RATES AMONG THERAPY PERSONNEL OF 20 PERCENT IN IOWA, 15 PERCENT IN PENNSYLVANIA, AND COMPARABLE AND GREATER VACANCY RATES IN OTHER STATES. IN RESPONSE TO THESE SHORTAGES, FACILITIES HAVE BEEN FORCED TO REDUCE SERVICES, CLOSE BEDS OR UNITS,AND DIVERT PATIENTS TO OTHER FACILITIES.

THE 1988 INSTITUTE OF MEDICINE (IOM) STUDY OF TEN ALLIED HEALTH PROFESSIONS ALSO DOCUMENTS THE CRITICAL NEED FOR ADDITIONAL MANPOWER AND NOTES THAT, ABSENT CONCERTED INTERVENTION TO TRAIN NEW PERSONNEL, THESE SHORTAGES WILL INTENSIFY FOR THE REMAINDER OF THIS CENTURY AND THROUGH THE YEAR 2020. IN PARTICULAR, THE IOM REPORT NOTED THAT THE MOST SERIOUS SHORTAGES BY THE YEAR 2000 WOULD BE IN THE OCCUPATIONAL AND PHYSICAL THERAPY PROFESSIONS.

THE HEALTH CARE COMMUNITY IS AGGRESSIVELY PURSUING A VARIETY OF STRATEGIES TO MEET THIS PROBLEM. FACILITIES ARE EXPANDING THE USE OF OVERTIME AND CONTRACT SERVICES, AND MAKING INNOVATIVE CHANGES IN COMPENSATION PROGRAMS AND SCHEDULING. PROFESSIONAL ASSOCIATIONS ARE COMMITTING RESOURCES TO THE DEVELOPMENT AND EXPANSION OF EDUCATIONAL PROGRAMS AND ADDITIONAL FACULTY AND STUDENT RECRUITMENT. HOWEVER, ADDITIONAL INCENTIVES TO INCREASE

THE SUPPLY AND DISTRIBUTION OF ALLIED HEALTH PROFESSIONALS ARE NECESSARY, AND FEDERAL SUPPORT FOR THESE EFFORTS IS ESSENTIAL. THE MOST CRITICAL IMMEDIATE NEED IS TO EXPAND PROGRAM AND FACULTY RESOURCES. EDUCATION PROGRAM SURVEYS CONDUCTED BY THE AMERICAN OCCUPATIONAL THERAPY ASSOCIATION AND THE AMERICAN PHYSICAL THERAPY ASSOCIATION CONFIRM THESE NEEDS. THE SINGLE MOST IMPORTANT FACTOR INHIBITING CAPACITY EXPANSION IDENTIFIED BY PROGRAM DIRECTORS IS THE AVAILABILITY AND RECRUITMENT OF QUALIFIED FACULTY MEMBERS.

FULL FUNDING OF THE ALLIED HEALTH EDUCATION AND TRAINING INITIATIVES AUTHORIZED UNDER TITLE VII IS CRITICALLY IMPORTANT TO THE OVERALL EFFORT TO ADDRESS THIS MANPOWER SHORTAGE. THE CAUCUS STRONGLY URGES THE SUBCOMMITTEE TO FUND THESE INITIATIVES AT THE FOLLOWING LEVELS:

SECTION 796 ALLIED HEALTH PROJECT GRANTS AND CONTRACTS -- $2 MILLION TO FUND THE DEVELOPMENT AND EXPANSION OF ALLIED HEALTH EDUCATION PROGRAM AND FACULTY RESOURCES AND EXPAND STUDENT ENROLLMENTS IN THOSE PROFESSIONS IN GREATEST DEMAND.

SECTION 797 TRAINEESHIPS FOR THE ADVANCED TRAINING OF ALLIED HEALTH PERSONNEL -- $2 MILLION TO ASSIST IN THE DEVELOPMENT AND EXPANSION OF DOCTORAL PROGRAMS AND TO PROVIDE FELLOWSHIPS TO INCREASE THE NUMBERS OF QUALIFIED FACULTY IN PROFESSIONS EXPERIENCING SHORTAGES.

SECTION 751 LOAN REPAYMENT PROGRAM FOR ALLIED HEALTH PERSONNEL -- $2 MILLION TO ESTABLISH A LOAN REPAYMENT PROGRAM FOR ALLIED HEALTH PROFESSIONALS WHO AGREE TO SERVE FOR NOT LESS THAN TWO YEARS IN A RURAL OR OTHER UNDESERVED AREA.

MR. CHAIRMAN, THE SUBCOMMITTEE MEMBERS MIGHT BE INTERESTED TO KNOW THAT WHILE $750,000 WAS APPROPRIATED FOR THE SECTION 796

PROGRAM FOR FISCAL YEAR 1990, THE BUREAU OF HEALTH PROFESSIONS RECEIVED OVER 2,000 INQUIRIES AFTER AVAILABILITY OF THE FUNDS WAS PUBLISHED IN THE FEDERAL REGISTER AND ULTIMATELY RECEIVED OVER 122 GRANT PROPOSALS PRIOR TO THE APPLICATION DEADLINE. WE ALSO KNOW THAT MANY MORE EDUCATIONAL INSTITUTIONS WERE INTERESTED IN SUBMITTING PROPOSALS BUT WERE HAMPERED BY THE SHORT TIMEFRAME AVAILABLE IN WHICH TO PREPARE APPLICATIONS. WE BELIEVE THIS IS ADDITIONAL COMPELLING EVIDENCE THAT THE NEED IS VERY REAL, AND THAT MORE FEDERAL LEADERSHIP IS REQUIRED TO MEET THIS CHALLENGE.

IN SUM, ALTHOUGH THE THREE TITLE VII INITIATIVES ARE MODEST WHEN MEASURED AGAINST THE ESCALATING DIMENSIONS OF THE PERSONNEL SHORTAGE, THEY DO REPRESENT AN IMPORTANT STEP TOWARD ADDRESSING THE PROBLEM AND ARE VITALLY IMPORTANT IF WE ARE TO MEET THE HEALTH CARE NEEDS OF THE ELDERLY AND DISABLED IN THE YEARS AHEAD.

AGAIN, MR. CHAIRMAN, ON BEHALF OF THE NATIONAL REHABILITATION CAUCUS, I THANK YOU FOR THIS OPPORTUNITY TO SHARE OUR VIEWS ON THIS IMPORTANT ISSUE.

SUBCOMMITTEE RECESS

Senator SPECTER. That concludes our hearings.

The subcommittee will stand in recess until 9:30 a.m., Thursday, March 22. At that time, the subcommittee will continue public witness hearings on the administration's fiscal year 1991 budget request and the hearings will be held in room SD-138. Thank you all.

[Whereupon, at 12:45 p.m., Wednesday, March 21, the subcommittee was recessed, to reconvene at 9:30 a.m., Thursday, March 22.]

DEPARTMENTS OF LABOR, HEALTH AND HUMAN SERVICES, AND EDUCATION AND RELATED AGENCIES APPROPRIATIONS FOR FISCAL YEAR 1991

THURSDAY, MARCH 22, 1990

U.S. SENATE,
SUBCOMMITTEE OF THE COMMITTEE ON APPROPRIATIONS,
Washington, DC.

The subcommittee met at 9:35 a.m., in room SD–138, Dirsken Senate Office Building, Hon. Brock Adams presiding.

Present: Senator Adams.

NONDEPARTMENTAL WITNESSES

Senator ADAMS. Good morning. Welcome this morning. I am pleased to be here.

This is the subcommittee's hearing from public witnesses and this morning, we continue with the third day of 6 days of public witnesses, the testimony focusing on programs funded by the Subcommittee on Labor, Health and Human Services, Education, and 20 related agencies.

The chairman, Senator Harkin, has asked me to preside and act as chairman this morning, and he sends his greetings to all of you, and I am pleased to be able to do this.

During the several sessions, the subcommittee will hear from approximately 150 witnesses. It is a matter of regret to all the members of the subcommittee that we had to limit the number of witnesses that we will be able to hear this year. You have all been very understanding about our time constraints, and I do want to assure you that witnesses who have their testimony to the subcommittee staff by April 9 will have that testimony put in the hearing record.

In order to help us stay on schedule, unfortunately, we are going to have to use the red light, green light system. As you know, based on the letter you received from Chairman Harkin, each witness has 3 minutes in which to present his or her oral testimony. When the red light goes on, your 3 minutes have expired. We need to ask each of you to conclude your remarks when the red light goes on so that each witness will have a fair and equal opportunity to be heard.

I would like to welcome all of you to the committee, and as you perhaps know, we have a list of 25 witnesses this morning.

STATEMENT OF IRENE S. POLLIN, PRESIDENT, LINDA POLLIN FOUNDATION

Senator Adams. The first witness on our list this morning is Irene Pollin, president of the Linda Pollin Foundation, an old friend, and I hope aid, as well. We will be pleased to hear from you, and if you want to start the light system on green, Ms. Pollin will know that she is on her way.

In every case, the chairman will make an order right now, that all statements that the witness indicates that they wish made part of the record, so that they can give an oral testimony, will be made part of the record as though given in full, so that if you just make that request, that will automatically be granted. That way, you may summarize your testimony, give it orally or in any fashion that you wish.

With that, Ms. Pollin, you are recognized.

Ms. Pollin. Thank you. Mr. Chairman and distinguished members of the subcommittee, my name is Irene Pollin. I welcome this opportunity this morning to discuss with you a subject of great importance to the health and well-being of an increasing number of people in our country who are undergoing treatment for chronic illness.

That subject is psychological support and intervention, a form of mental rehabilitation. Sometimes, I describe this type of rehabilitation as short-term therapy for long-term illness.

Today, I am speaking from three points of view: my 16 years of experience as a professional psychotherapist, as a mother of two children who were born with and died from severe congenital heart defects and, three, president of the Linda Pollin Foundation, a foundation which was established several years ago by my husband Abe and myself, in memory of our daughter, Linda.

This foundation is dedicated to promoting medical crisis counseling programs for health care professionals who counsel patients and families when they are coping with all of the emotional problems that are caused by chronic illness. I urge the subcommittee to consider the following: One, to ensure the continued funding of research, which is the effectiveness of these counseling services; two, ensure funds for training clinicians to carry out their research; and three, to encourage the provision of high quality counseling services as part of the total medical care offered in federally supported programs, for example, in all federally funded medical centers of excellence.

PREPARED STATEMENT

Improved medical treatment has increased survival rates in our wonderful country, but we have not addressed the quality of that extended life. As a society that cares about its citizens, we owe these people, not only an increased lifespan, but a reason to live.

Thank you for this opportunity to present the views of the Pollin Foundation.

[The statement follows:]

STATEMENT OF IRENE S. POLLIN

I welcome the opportunity to discuss with you today a subject which is of great importance to the health and well-being to the large number of people in our country who are undergoing treatment for chronic illnesses. That subject is psychological support and intervention, a form of mental rehabilitation. Sometimes I describe this as short-term therapy for long-term illness. What does it mean? It means meeting with patients on a regular basis, following an individualized workplan until resolution of basic issues has been reached.

My name is Irene Pollin. I serve as President of the Linda Pollin Foundation and a member of the Presidentially appointed National Cancer Advisory Board. I am a licensed social worker and have created three out-patient counseling centers for the chronic medically ill, the most recent at the Washington Hospital Center here in Washington, D.C.

THE LINDA POLLIN FOUNDATION

Today, I am speaking in the capacity of founder and director of the Linda Pollin Foundation which is dedicated to improving the availability, quality and delivery of mental rehabilitation to the chronic medically ill and their families. The Foundation was established by my husband Abe and me in memory of our daughter, Linda, who was born with a series of severe heart defects and died at age sixteen after open heart surgery.

THE CHRONIC MEDICALLY ILL

Advances in medical research have made it possible for people suffering from a number of chronic illnesses to survive for longer periods of time. I know I can speak both for the Foundation's Board of Trustees and the National Cancer Advisory Board in commending our Nation's research efforts which have caused this result to come about. The focus of the Foundation's interest is in training qualified people as well as creating new centers where these people who must cope with illness for the rest of their lives can learn to cope with the emotional issues attending them.

It is imperative that we begin to turn our attention now to the psychosocial needs of these individuals through the health care systems where they are receiving primary treatment. Interventions such as Medical Crisis Counseling can help individuals reduce their sense of isolation, regain their sense of control and again be in charge of their lives.

ADVOCATES FOR CHANGE

There are three ways in which the support for counseling can be incorporated into programs presently supported by the Federal Government:

1. CONTINUED FUNDING OF RESEARCH INITIATIVES WHICH ASSESS THE EFFICACY OF COUNSELING SERVICES

Interest in the science of behavioral research which includes adaptation to chronic disease and familial dysfunction that results from prolonged periods of stress associated with chronic disease is relatively new.

For example, the National Cancer Institute sponsored the first conference on psychosocial and behavioral research in 1975. Results from that effort as well as other public and private endeavors have been helpful in improving the quality of life of patients which chronic disease but now we need to strengthen and build on those efforts.

The Pollin Foundation believes that additional research is necessary particularly on where resources, human as well as financial, can best be directed. For example, questions need to be asked on:

~ With which patients and families should professionals intervene?

~ Which people will most benefit from support groups?

~ What is the best timing for intervention?

~ Which interventions are most effective with which physical symptoms?

All of these research questions need to be answered as they will play a major role in improving the quality of life of these people, decrease the cost of health care and return many of these people to their former level of productivity.

Even though some studies have begun to show the benefits of counseling on survivors, many questions remain unresolved. How do we insure compliance with medical protocol, and how do we help patients to become fully functioning individuals?

2. TRAINING OF SCIENTISTS AND CLINICIANS TO CARRY OUT THESE RESEARCH INITIATIVES

As we continue to improve the quality of our health care, so we increase the number of people who need mental rehabilitation. We will need a cadre of trained individuals to work with these people.

Programs to train mental health professionals who can deliver high quality services are scarce. Recognizing this dearth of training, Abe and I founded the Pollin Foundation two years ago. We presently have five fellows in training at outstanding academic institutions such as UCLA, Memorial Sloan Kettering, University of Maryland, Massachusetts General Hospital and the University of Pennsylvania. They are psychiatrists, psychologists, social workers and nurses. They are all post-doctoral students. Their additional charge is to create new clinics where Medical Crisis Counseling services will be available.

We strongly urge this committee to ensure that Federal dollars are available throughout the United States to support this type of research and training. This can be done in appropriate federal agencies. And we strongly urge this committee to request specific funds to support multidisciplinary team and collaborative endeavors because no single discipline can alone provide tools and expertise for the type of comprehensive research which is needed to address the problems.

3. ENCOURAGE ENTITIES WHICH RECEIVE FEDERAL FINANCIAL SUPPORT TO INCORPORATE MENTAL REHABILITATION SERVICES AS PART OF THEIR TOTAL MEDICAL CARE

It is known that patients and families armed with appropriate information, emotional support and techniques which teach and strengthen existing coping skills do learn to live with and adapt successfully to a lifetime of chronic illenss. At the same time, few medical practitioners recognize when or how to offer ways to alleviate psychosocial stresses. The Pollin Foundation urges Congress to include in existing federal programs the ability to:

~ Provide multidisciplinary training programs which incorporate psychosocial intervention;

~ Provide multidisciplinary research trials in federally support research programs;

~ Provide clinical intervention services as a part of the medical care offered in Federally supported programs. For example, in all federally funded Centers of Excellence.

SUMMARY

As a mental health professional who has specialized in working with the chronically ill and their families, I have observed that patients with chronic disease seek not only a hopeful prognosis and a humane and caring medical treatment, but psychological support -- something which is missing in today's delivery of medicine. This public interest has been brought to the attention of Members of Congress resulting in a recent study by the Office of Technology Assessment. Their charge has been to review various unconventional treatments for cancer including psychological ones. Unfortunately, there still are a number of psychological therapies which are questionable to me. On the other hand, a renowned traditional medical institution, the Institute of Medicine, is about to embark on their own study. On behalf of the Pollin Foundation, therefore, I request that you consider inserting in the report which accompanies the appropriations bill language which encourages the provision of high quality counseling services as a part of any medical care offered in federally support programs.

Thank you for your consideration.

Senator Adams. Thank you, Ms. Pollin.

Could you tell us a little bit more about the medical crisis counseling and how, maybe, we should incorporate it into the federally supported centers?

Ms. Pollin. Yes; I would be happy to. Medical crisis counseling is a term that I came up with which represents the short-term therapy which helps chronically ill patients and their families cope with all the various issues, financial, practical, and emotional, that result from coping with their chronic illness over a long period of time.

It can be incorporated into the total medical care of all of these patients. For example, I visited, last week, the M.D. Anderson Cancer Clinic in Houston, TX, in my role as a member of the National Cancer Institute. There is incredible research, it is an incredible facility, one that I am proud of as an American citizen. And they do outstanding counseling by a number of various mental health professionals.

The problem was, as I saw it, that it was episodic and inpatient. What I believe these people should have is the full benefit of rehabilitation from bedside to deskside. Unless it is available to them in a formalized outpatient service, I do not believe that is possible.

Senator Adams. Thank you very much. Thank you too for being with her this morning, Abe. I am glad to see you again. It is a pleasure to hear your testimony.

STATEMENT OF MARTIN W. ADLER, EXECUTIVE SECRETARY, COMMITTEE ON PROBLEMS OF DRUG DEPENDENCE

Senator Adams. Our next witness is Dr. Martin Adler, executive secretary on the Committee on Problems of Drug Dependence. Welcome, Dr. Adler, we look forward to hearing your testimony.

Dr. Adler. Mr. Chairman, members of the subcommittee, my name is Martin Adler. I am a professor of pharmacology at Temple University School of Medicine, Philadelphia, PA. I am appearing today as executive secretary of the Committee on Problems of Drug Dependence or the CPDD, and we appreciate the opportunity to present our recommendations and views about funding for the National Institute on Drug Abuse.

CPDD was organized in 1929 as the oldest scholarly society devoted to research in the area of drug abuse in the United States.

We are sponsored by 10 major scientific and professional organizations, and our panel, or board of directors, comprises the most outstanding members of the basic research and clinical research science.

I am here today to request that Congress appropriate sufficient funds to both continue and expand drug abuse research at the National Institute on Drug Abuse. Today, there are an estimated 1.2 million chronic IV drug abusers. Over 22 million Americans have tried cocaine; 30 percent of recently diagnosed AIDS patients are IV drug users, and 70 percent of all AIDS babies are the children of IV drug abusers.

It should be pointed out that in the fiscal year 1991 budget proposed by the administration, drug abuse comprises only one-half of 1 percent of the total, Federal research and development budget.

Although CPDD strongly supports the administration's fiscal year 1991 proposed budget for NIDA, we are disappointed that the President's budget actually decreases the number of new and competing research project grants from 278 to 245. This is an alarming development and should not, we believe, be countenanced by the committee.

In the area of training, we strongly support the proposed increase in institutional and individual training awards. NIDA-supported research will continue to increase our understanding of the basic pharmacological and behavioral mechanisms of abused drugs as an aid in understanding and developing strategies for treating and preventing drug abuse.

I would like to digress for just one moment, and say something about the issue of animal rightists and the disruptive influence that it is having on research in this field today. We need more animal models, and yet primates, which are the principal models to be used, the use of these animals has gone down 62 percent in recent years. This, despite the fact that we are increasing the number of drug abusers in the United States.

I would be remiss if I failed to mention the positive effect that NIDA-supported research has had on other areas of research, and in improving health. Work supported by NIDA contributes significantly to our understanding of brain functions and the treatment of many diseases of the brain.

In conclusion, we need continued, stable funding for drug abuse research. Despite the increase in funds over the past few years, there has not been stability and consistency in this growth. The expansion of drug abuse research in fiscal year 1987 was not upheld in 1988, and from fiscal year 1989 to fiscal year 1990, funds for non-AIDS initiatives declined by almost 30 percent. The lack of stability discourages young scientists from entering the field due to a perceived lack of commitment to the area.

PREPARED STATEMENT

Development of new medications to aid in the treatment of drug abuse is a top research priority of NIDA, but additional funding for this is needed.

I thank you very much for your time and for hearing our testimony.

[The statement follows:]

STATEMENT OF MARTIN W. ADLER

Mr. Chairman and Members of the Subcommittee, my name is Martin W. Adler, Ph.D. I am Professor of Pharmacology at Temple University School of Medicine in Philadelphia, Pennsylvania.

I am speaking today as Executive Secretary of the Committee on Problems of Drug Dependence, or CPDD. We appreciate this opportunity to present our views on drug abuse research.

CPDD, organized in 1929, is the longest-standing scholarly society in the United States aimed at addressing the problem of drug abuse in this country. Today, CPDD is composed of a multidisciplinary panel sponsored by ten professional medical and scientific societies on which many of the most distinguished basic science and clinical researchers in the area of drug abuse serve. The Committee has three principal functions. First, we test all new therapeutic compounds being developed to treat diseases of the brain to determine their potential to produce drug dependence or abuse. Second, we hold the major scientific annual meeting in the U.S. in the field of drug abuse. Finally, we function as an information resource for national and international government agencies on issues relating to drug abuse and dependency.

I am here today to request that the Congress appropriate sufficient funds to promote the continuation and ensure the expansion of drug abuse research at the National Institute of Drug Abuse (NIDA). Drug abuse is a major problem confronting today's society. Today, there are an estimated 1.2 million chronic intravenous drug abusers. Over 22 million Americans have tried cocaine. 85% of high school seniors say it is easy to purchase marijuana; 54% say it is easy to buy cocaine. 30% of recently diagnosed AIDS patients are intravenous drug abusers. 70% of all AIDS babies are the children of intravenous drug abusers.

Basic research into the prevention and treatment of drug abuse and dependence is therefore among the most critical needs of our time. The societal costs of drug abuse continue to mount at an alarming rate and the problems have reached every neighborhood in America. The cost of treating addiction mounts steadily as well. It has been estimated that the health costs of caring for drug addicts now exceed $50 billion.

In view of the prevalence of drug abuse in this country and in light of the President's pledge to combat this critical problem, we must ensure that sufficient resources are appropriated for drug abuse research. In light of our limited resources, the decision is a difficult one; but one factor that must be considered is how much money is currently spent on drug abuse research compared to other programs. In the FY 1991 budget, research on drug abuse comprises one half of one percent of the total federal research and development budget. In 1991 alone, more money will be spent on cancer research than has been spent on drug abuse research over the last 18 years. Comparison of drug abuse budgets to defense or other budgets makes it clear that we do not have now nor ever have had a "war on drugs." If our society wants to make a long-term commitment to the prevention and treatment of drug abuse research, Congress must continue to support additional funding of drug abuse research.

The Administration's FY 1991 proposed budget calls for $373,736,000 for research and demonstration projects at the National Institute on Drug Abuse. This budget proposal represents an increase of approximately 19 million or 9.4% over the FY 1990 comparable for research, but unfortunately provides a $9 million decrease in treatment demonstrations. This proposal would allow NIDA to award 245 combined new and competing grants, 551 continuation research project grants and 24 drug abuse research centers.

CPDD strongly supports the Administration's proposal for NIDA for fiscal year 1991. CPDD, however, is disappointed that the President's budget actually decreases the amount allocated for NIDA-supported treatment demonstrations. A current services level in this account should be continued -- at a minimum. We also are disappointed that the proposed NIDA budget actually decreases the number of new and competing research project grants, from 278 to 245. This development is alarming and should not, we believe, be countenanced by this Committee.

Moreover, we support the President's increased funding proposal for the treatment improvement program at ADAMHA's Office of Treatment Improvement (OTI). Nonetheless, we cannot support "zeroing out" OTI's drug waiting list program, as the President proposes. Indeed, we believe that NIDA's OTI should be allowed to target cities for treatment improvement support on its own authority, without interference from OMB.

Finally, we do strongly support this proposed increase in both institutional -- from 126 to 154 -- and individual -- from 29 to 44 -- training awards in this budget. This is a significant increase and should be applauded.

Significant advances have been made in the field of drug abuse as a result of NIDA funded research. In the area of drug abuse prevention, NIDA supported research has resulted in a 50-75 percent short-term reduction in cigarette smoking among junior high school students. This research should be expanded to determine the long-term efficacy of these programs and the application of these principles to other drugs of abuse. Ongoing studies have demonstrated that increasing the confidence and self-esteem levels of the young helps them resist peer pressure to become drug abusers. Additional research funded by NIDA has also focused on the question of vulnerability by exploring whether certain persons are more predisposed biologically than others to substance abuse. Research has already begun on the brain wave pattern of certain parents and their children which indicates a potential genetic pre-disposition of substance abuse.

The NIDA research will help us increase our understanding of the basic pharmacological and behavioral mechanisms of abused drug action and develop strategies for preventing drug abuse in the future. The prevention of drug abuse is a far better alternative than its treatment. Preventing drug abuse will also lessen the transmission of AIDS by intravenous drug abusers. We, therefore, urge the Committee to ensure that a fair portion of the funds allocated to non-AIDS research will be allotted to drug abuse prevention.

Significant progress also has been made in the area of treatment of drug abuse. Financial support from NIDA has enabled researchers to develop a new drug, naltrexone, the only pharmaceutical agent other than methadone that has been approved for the treatment of drug abuse. This drug is being used widely and is saving thousands of lives today. NIDA-funded research has also been instrumental in the production of an antibody against PCP that may be useful in treating its toxic effects. Finally, new procedures have been developed to reveal drug induced neuropathology and to detect drugs in the urine.

One of the principal benefits of NIDA-funded research is the positive effect it has had on other areas of research aimed at improving health. Due to the significant progress that has been made in drug abuse research, substantial progress has also been made in other scientific, biomedical and behavioral research areas. Indeed, work supported by NIDA contributes to our understanding of brain functions and the treatment of many diseases of the brain.

Continued stable funding for drug abuse research is essential not only to support existing programs but also to ensure a stable base of new funds for which scientists can compete. Although the drug abuse research program has been greatly expanded over the past several years, there has not been stability and consistency in this growth. The expansion of drug abuse research in FY 87 was not upheld in FY 88. Funds available for new initiatives declined by nearly 45 percent. New funds for non-AIDS initiatives declined by almost 30 percent from FY 89 to FY 90. This lack of consistency in the non-AIDS budget makes it difficult to conduct an orderly expansion of the drug abuse research program. In addition, it discourages young scientists from entering the field of drug abuse research due to a perceived lack of committment to the area.

Additional funding is essential to continue making significant advances in the field of drug abuse. Development of new pharmacotherapeutics to aid in the treatment of drug abuse is the number one research priority of the Institute. We endorse this initiative, which was championed by Mr. Conte, the ranking Member of this Committee. Among the thousands of pharmaceuticals available today, only two, methadone and naltrexone, have been specifically developed to treat the problem of drug abuse. We need new drug treatments for chronic cocaine users. Three drug products show immediate promise of offering clinical utility in the area of drug abuse. Funds provided in the Anti-Drug Abuse Act of 1988 allowed NIDA to expand its drug development efforts and to create a focused program aimed at developing drugs for the treatment of addictive disorders. Additional funding, particularly for contracts, will be necessary in FY 1991 to maintain this initiative and allow the development of promising new drugs.

Additional funding also is necessary to expand research on the neural basis for genetic predisposition and vulnerability to drug abuse on the treatment of cocaine abuse and on the effects of maternal drug use on infant development. More qualified scientists are needed to expand the drug development program. The expansion of drug abuse research in the past several years has been made possible by the ability of NIDA to attract scientists from other areas. But the continued success of the program will require a major investment in training young scientists in special techniques necessary for drug abuse research. Shortages of trained scientists are already being encountered in certain areas. More chemists and pharmacologists are required to expand the drug development program and more clinicians are needed to conduct clinical trials of new drugs. Accordingly, we request that clinical training support for NIDA, both for basic and applied training, be included again this year for NIDA/NIAAA as it is for NIMH, and which was the case in FY 1990.

In conclusion, the problem of drug abuse pervades our society and has a tremendous impact on human and economic conditions. As a result of NIDA-funded research, significant strides have been made in the areas of prevention and treatment of drug abuse. This progress must continue. Indeed, we salute the leadership of ADAMHA's Administrator, Dr. Frederick Goodwin, NIDA's Director, Dr. Bob Schuster, and the OTI Director, Dr. Beny Primm. We, therefore, strongly support the Administration's increased appropriation for non-AIDS research at NIDA. Still, we believe additional funding will be necessary to restore the research initiative begun in 1987 and provide the essential resources for the orderly and promising growth and expansion of drug abuse research. Accordingly, we urge the Committee both to support and expand the President's budget proposal so that we will ensure that we reach this objective.

I thank you for this opportunity to appear before you and I am grateful for your outstanding leadership in the past in providing funding for research in this critical area. I would be pleased to answer any questions at this time.

Senator ADAMS. Thank you, Dr. Adler. How much of an increase are you seeking for NIDA?

Dr. ADLER. Well, rather than just setting specific numbers, the Mental Health Coalition has come up with specific figures in their testimony. They will refer to that later. And the report is out, and we fully support——

Senator ADAMS. And you support that?

Dr. ADLER. Yes; we do.

Senator ADAMS. Thank you very much, Doctor, we appreciate your testimony.

STATEMENT OF HUGHLETT L. MORRIS, UNIVERSITY OF IOWA, ON BEHALF OF THE AMERICAN ASSOCIATION FOR DENTAL RESEARCH

Senator ADAMS. Our next witness is Prof. Hugh Morris, University of Iowa, American Association for Dental Research, and Chairman Harkin wanted to express his regrets that he was not here this morning, and I am giving them to you for him.

Mr. MORRIS. Thank you, and we are perfectly pleased to have you here.

I am here to talk about the work which is done by the National Institute of Dental Research and particularly that part of it that has to do with head and neck birth defects. These are defects which occur about once in 700 births, and they are the most frequently occurring, major birth defects that we have.

They affect the way the child looks, they affect the way the adult looks, they affect his or her teeth and they affect the way that he or she talks. And they particularly affect the way that the child performs in school and the way that the adult performs as she or he looks for work and tries to live a normal life.

The Institute and we have made great headway in the last 30 years, and I talk about the kind of thing that we have done in my statement, but we have three major needs that we need to move on to. One of them is that we need to get better in knowing how to prevent the defects, and one is that we need to know more about ways in which to get the good care that we now know that we can provide to all of the people.

PREPARED STATEMENT

The third one is that we still have 20 percent of the total group who have a lot of problems all along, and we need to get smarter at handling those. And the fourth great need is that we need to be sure to train young doctors and young scientists who can help us meet those first three research needs.

Thank you.

[The statement follows:]

STATEMENT OF HUGHLETT L. MORRIS

Mr. Chairman and Members of the Committee—

My name is Hughlett L. Morris, Ph.D., Professor of Speech Pathology and Director of the University of Iowa Cleft Palate Research Program.

Thank you for the opportunity to make this presentation on behalf of the American Association for Dental Research (AADR).

The membership of the AADR consists of over 4,000 scientists from a variety of basic science and clinical disciplines located in universities, research institutes, hospitals, and industrial laboratories around the country. Our principle objective is to study the causes of the major diseases affecting the oral/facial region, and to seek ways of treating or preventing these diseases.

Scope of Dental Science

The field of dental science is broad in that it covers a multitude of oral diseases which afflict the mouth, teeth, and jaws. It explores all aspects of oral tissue growth, development, aging, maintenance, and repair, taking into consideration the dynamics of the oral environment as well as chemical, genetic, immunological, microbiological, hormonal, neural, nutritional, and behavioral variables that affect oral structures and functions.

Research is also conducted on craniofacial developmental abnormalities such as cleft palate, on genetic diseases affecting teeth and bones, on facial trauma and wound healing, on the salivary glands, and on sensori-motor functions such as taste, chewing, and swallowing, and on the perception and control of pain, wherever it occurs in the body.

While all of these components merit comment, I want to focus on research about orofacial/craniofacial birth defects. My credentials are those of a doctor of speech pathology with 35 years of clinical and research experience with these babies, children, adults, and their families.

These defects of the mouth, face, and sometimes head, are the most frequently occurring major birth defect experienced by humans, occurring in about 1 in 700 live births. They are the result of incomplete development, mostly, of these structures during early months of pregnancy that leads to a cleft lip and/or cleft palate at birth in the majority of these patients. There are other malformations as well, some affecting appearance and others affecting the function of the body.

As you can imagine, these birth defects are not life threatening but cause a number of serious problems for the person with the defect and his or her family.

The Clinical Consequences of Cleft Lip and Palate

To begin with, we must conclude, on the basis of present evidence, that in humans the majority of these defects are genetic in origin. We know that they can be caused by a number of early pregnancy conditions in several research animals but the supporting evidence for humans *is scant. This likelihood of a genetic cause sets the stage for perceptions and feelings about the disorder experienced by patient and her/his family throughout a lifetime.*

If there is cleft lip or other visible malformations the patient will need reconstructive surgery at the appropriate ages and, even so, will be almost certain to have physical appearance throughout life that is significantly "different".

If there is cleft palate, there is high probability of speech problems that result from the structural malformations as well as from the individual's attempt to compensate for the malformations.

Nearly all these patients have dental problems ranging from malocclusion to marked facial growth retardation. Further, there is always need to deal with the complicated interactions between dental status and surgical reconstruction, and dental status and speech patterns.

These patients have additional problems to deal with as well. Many require special assistance in feeding; most have an unusually high frequency of middle ear disease until they start school; some need treatment for associated birth defects (malformed external ear or limbs, or defects of the internal organs such as the heart); and some experience difficulties in school that seem to be related to specific learning disabilities.

This brief review of the clinical consequences of this one kind of head and neck birth defect is intended to indicate the severity of the disorders, their complexity, and the magnitude of health, education, and social care costs required for their satisfactory treatment.

Accomplishments During the Past 30 Years

Two objectives of the National Institute of Dental Research are to promote and support research designed to improve treatment of dental related disorders and to reduce treatment costs. I have been associated with these efforts since the Institute was established, and I am pleased to report our considerable success in cleft palate with support from NIDR-supported research and development projects. Following are some examples of our success.

Item. Fifty percent of the children who had cleft palate surgery in 1960 would need a second surgery before there was reason to expect speech that is normally oral. By virtue of improved methods that percentage is now 20%.

Item. In 1960, in standard practice speech therapy was provided children and adults with cleft palate, if there was disordered speech, in shot gun fashion, even if no progress was observed. In 1990, therapy is provided only if our improved methods indicate reason for expecting improvement. I estimate this constitutes a 35% reduction of therapy.

Item. More efficient orthodontic treatment methods and more conservative surgery makes it feasible to perform reconstructive surgery at 12 months (or earlier) for the child treated in 1990 whereby treatment for the same child in 1960 was delayed until the age of 24 months (or *older). Frequently the child develops abnormal speech patterns when surgery is delayed, to be avoided if at all possible.*

Item. On the average, the young adult with cleft in 1990 is more similar to his/her "normal" counterpart in social, educational, vocational aspects than was the young adult with a cleft in 1960.

Item. Our current understanding of dental caries and dental crown and bridge technology (both advances the results of other NIDR programs) has led to an impressive increase in the ability to save teeth and to use fixed dental prosthetics for the 1990 patient with a cleft, thus eliminating the need in many cases for the cumbersome and expensive removable dental prostheses used by the 1960 patient.

Item. The infant and young child in 1960 had many episodes of middle ear disease that were undetected and hence untreated, probably resulting a worsening of their problems in learning normal language and speech. The 1990 child is examined periodically for ear disease and treated promptly if symptoms are discovered.

The Needs of the Future

This brief review of accomplishments, of real benefits to the patient and his/her family, is clear evidence of the success of programs conducted jointly by NIDR and research teams that are represented by the AADR.

Our remaining task here is to identify problems to be resolved and questions to be answered that are highest priority.

Item. Technologic advances in human genetics place within our reach the ability to identify genetic aspects of cleft palate and other related disorders. Once gained, this ability will enable a level of family planning not previously possible. These research efforts require extensive participation by developmental, cell, and molecular biologists as well as geneticists.

Item. There is yet much to learn about the mechanisms of dental and facial growth about the influences that cause growth disorders in children and adults with these defects. One of every five cleft lip and palate patients continues to show growth disturbances that seem unexplainable by our present knowledge. These disturbances give the patient an unusual facial appearance and frequently cause impairment in speech and mastication. Again, this work will require important contributions by the research biologist.

Item. A parallel need is to better understand the mechanisms of oral function that seem behavioral in nature. These problems are at once simple and complex. For example, there are aspects of both speech and deglutition (chewing, swallowing) that are virtually automatic and highly resistant to disruption. At the same time, when there is a disturbance in normal structure or development, especially in newborn, a different set of rules appear in command, and those rules must be better understood before the human distress is resolved. In work of this kind, the dental research team must include such disciplines as speech pathology.

Item. I reported earlier that considerable information is now available about treatment methods that generally give satisfactory results in some 80% of the patients. There is much yet to be learned about ways to better treat the remaining 20%, the so-called problem cases; ways to further refine today's methods that are deemed satisfactory (for example, making them more cost efficient); and for ways by which satisfactory treatment is available to more people as a matter of course in the delivery of health care.

Some of these objectives fall under the umbrella of determining treatment efficacy (which treatments give best results). NIDR has well-established interest in supporting investigations of this sort and is anxious to promote them. Results from these studies are badly needed for answering questions about treatment frequently asked by the public. On the other hand, these studies are not easily designed or conducted, because of the necessary scientific rigor, and frequently are very expensive.

Item. There is continued need for young scientists to continue this important work. We need young biologists, biochemists, and speech scientists to help us better understand the development and mechanisms of oral disease and oral function and we need young scientists also who are clinicians since it usually is they who link the laboratory findings to the patient.

Budgetary Needs

While we are fully aware of the difficult budgetary pressures facing the Congress, we believe that adequate funding of the Nation's biomedical research enterprise can be achieved through a re-ordering of the priorities in the President's budget.

It is with this in mind that we respectfully request a funding level for the National Institute of Dental Research of $210 million for the FY 1991. This level will allow for a balanced research program in dental science, by supporting regular research grants, research centers, training, and intramural research.

Mr. Chairman, the Association supports the NIH funding level of $9.2 billion recommended by the Ad Hoc Group for Medical Research Funding.

I also wish to call your attention to the Biomedical Research Support Grant program, which is cut back in the budget. This program is designed to meet emerging opportunities in research, to pursue new ideas, and to develop young scientific talent and it has become an important part of dental research in this country. We urge the committee to provide funding at $96 billion.

This concludes my testimony and I will be happy to answer any questions.

Senator ADAMS. Thank you very much, Doctor. You answered my question already, of the number of children born. One in 700 births, is that correct?

Mr. MORRIS. Yes.

Senator ADAMS. We thank you for your testimony.

STATEMENT OF KENNETH L. BRIGHAM, AMERICAN LUNG ASSOCIATION

Senator ADAMS. Our next witness is Dr. Kenneth L. Brigham, American Lung Association.

Dr. Brigham, welcome.

Dr. BRIGHAM. Thank you, Senator. My name is Kenneth Brigham. I am president of the American Thoracic Society, which is the medical and scientific arm of the American Lung Association. We have submitted a written statement, which I request be incorporated into the record.

Senator ADAMS. Without objection, the entire statement will be included in the record as given.

Dr. BRIGHAM. Thank you.

The job I get paid for is being professor of medicine at Vanderbilt University, and in that role for the last 14 years, I have directed a specialized center of research in lung diseases.

The center mechanism was begun about 20 years ago with really two main purposes. One was to bring investigators from a broad array of disciplines together to address specific problems directly relevant to diseases of the lungs, which were a clinical problem. And the other was to juxtapose basic and clinical research in the same programs in order to assure that the right questions were asked and in order to assure that the translation of information from basic science to the bedside was made as rapidly as possible.

There are some remarkable successes of this program, and those could be enumerated, which have impacted directly and dramatically, on the diseases that affect human beings.

In my view and the view of many of us involved in this program, there now is a crisis in this program. It is the consequence of the fact that there has been essentially stable funding of the center program for the last several years, during a time when there has been a requirement that new areas be addressed by the establishment of centers in new areas, and the cost of research has increased.

As a consequence, the funding of these centers has been reduced, this year, to the magnitude of 20 percent below the recommended level of funding for the research that was approved to be done.

These kinds of reductions impact dramatically on the programs. They reduce the research that can be done. For example, in our case, we cannot pursue promising new therapies in acute lung injury because the funds will not be available. We cannot pursue the development of innovative new techniques for detecting a lung injury early in the course of the disease when it might be more amenable to therapy.

A number of other things could be listed from our program, as well as others, which simply cannot be done because the budgets have been reduced below the amount of which is clearly necessary to conduct the research.

PREPARED STATEMENT

For that reason, our association is supporting a request for an increase in funding in the center item. We believe that is justifiable on the history of the center mechanism and the impact that the mechanism has had on the prevention and cure of diseases in the lungs.

Thank you.

Senator ADAMS. Thank you very much, Doctor.

I gather that your increase, that you have mentioned in the last page of your testimony to begin new SCOR programs, would include areas like vascular biology and sudden death?

Dr. BRIGHAM. That is correct.

Senator ADAMS. Thank you very much, Doctor. That was my only question.

[The statement follows:]

STATEMENT OF KENNETH L. BRIGHAM

Mr. Chairman and Members of the Subcommittee, the American Lung Association and the American Thoracic Society, ALA's medical section, thank you for this opportunity to comment on the health and biomedical research programs in the FY 91 budget. I am Dr. Kenneth L. Brigham, President of the American Thoracic Society. In my professional capacity I am Professor of Medicine and Director of the Center for Lung Research at Vanderbilt University Medical Center, Nashville, Tennessee.

At the outset, Mr. Chairman, I would like to thank you and the Subcommittee for your support of biomedical research programs. This support is critical in view of the attempts by the Administration to limit support for health related research.

The ALA/ATS has reviewed the lung related research, training and demonstration programs for the National Institutes of Health and other agencies conducting activities related to the prevention and control of lung disease. The recommendations we make today represent our best estimate of the adequate resources necessary to continue these programs at the level of priority funding indicated by the magnitude of the lung disease problem. The funding levels include recommendations for AIDS activity, as appropriate.

SUMMARY: FY 91 HEALTH APPROPRIATIONS RECOMMENDATIONS (in millions)

National Heart, Lung and Blood Institute	$1,307.8 M
National Institute of Allergy and Infectious Diseases	1,116.3 M
National Institute of Environmental Health Sciences	279.4 M
National Institute for Occupational Safety and Health (CDC)	103.7 M
Tuberculosis Project Grants (CDC)	36.0 M
Office on Smoking and Health (CDC)	5.0 M
Office of Health Promotion (CDC)	5.0 M

Diseases of the lung constitute a devastating and growing health problem in the U.S. In 1988, it was estimated that over 84.9 million Americans had chronic respiratory disease, a categorization including seven conditions ranging in severity from chronic sinusitis to asthma, and emphysema. There is growing concern regarding the increased morbidity from asthma, now ranked 16th among all diagnoses. The prevalence of asthma in males increased 24% between 1980 and 1988 while in females, the rate increased 40%. In the aggregate, lung diseases including lung cancer, ranked third among the leading causes of death in 1987. Chronic Obstructive Pulmonary Disease (COPD) and allied conditions were the most rapidly increasing of the top ten leading causes of death between 1979 and 1987. The age-adjusted death rate due to COPD increased 28.1% in this same period. The combined direct and indirect costs of lung diseases were a staggering $45 billion in 1988.

Grim as this statistical picture appears, it is not hopeless. Federal programs for disease prevention and health promotion, biomedical research, environmental and occupational health hazard control, and professional education and training have greatly improved the detection and treatment of many lung diseases.

Major advances in both basic and applied knowledge of lung disease have occurred in the 20 years since the National Heart Institute was reorganized into the National Heart and Lung Institute, now the National Heart, Lung and Blood Institute. The NHLBI, through its Division of Lung Diseases, is the primary source of federal funds for lung research and in this twentieth anniversary year it is appropriate to comment on this Institute and its lung related research efforts.

The NHLBI research portfolio supports several research mechanisms. **Research Projects** support basic research and small-scale clinical studies. **Research Centers** are used to support multi-disciplinary research focused on major disease entities. This mechanism is also utilized to ensure that fundamental research outcomes are rapidly made available in the clinical arena. **Research Contracts** provide the primary mechanism used to support large clinical trials and other population-based studies.

In the last decade the Institute has experienced a growing imbalance in the research program as steps have been taken to stabilize funding for research projects, the keystone of the Institute's research program. The continuing imbalance has caused critical funding problems in other research areas, in particular for Research Centers.

Prior to discussing the specific funding problems within the Research Centers program and options for their resolution, it is important to understand the function and role of this program. Initiated in 1971, the NHLBI now supports 64 Specialized Centers of Research--SCORs. The SCOR program was developed to advance basic knowledge and to generate the most effective methods of diagnosis, management, and prevention of a variety of diseases including lung disease. Funded on a competitive basis for 5 years, SCORs are designed to encourage the concentration of research resources, facilities and personnel on selected research issues. The multidisciplinary nature of the SCORs combined with a focus on network coordination provides a valuable compliment to the other research mechanisms within the NHLBI research portfolio. The SCOR program is uniquely capable, because of its emphasis on both basic and clinical research, to ensure translation of advances in basic sciences to the clinical setting, thereby directly benefiting the patient and public health in general.

Seven SCOR programs are managed by the Division of Lung Diseases including:

o **Chronic Diseases of the Airways.** There are four SCORs in this research area conducting 21 separate research activites on both reversible and irreversible chronic airways diseases, chronic bronchitis, emphysema, and the pulmonary impairment of asthma. Basic mechanisms associated with the onset and progression of disease are under study as well as activity to improve management of these diseases through identification of presymptomatic stages, critical assessment of current therapeutic measures and development of more effective regimens.

o **Respiratory Disorders of Neonates.** The six SCOR programs in this area have developed 38 projects for improving the diagnosis, management, and prevention of respiratory disorders in newborns and children. Previous activities have emphasized neonatal respiratory distress syndrome and the role of surfactant. Future activity will explore the sequelae of bronchopulmonary dysplasia and apnea of prematurity.

o **Pulmonary Vascular Diseases.** Pulmonary edema, pulmonary hypertension, and pulmonary thromboembolism are the major disorders under study in the two SCORs in this research area. A total of 11 projects are under way to improve the diagnosis and management of these disorders through better understanding of the fundamental mechanisms associated with acute and chronic lung injury resulting in pulmonary vascular disease.

o **Occupational and Immunologic Diseases.** Four sites are managing 25 projects exploring fibrotic and granulomatous lung disease of unknown etiology. Also under study are lung diseases resulting from exposure to inhaled organic or inorganic substances found in the occupational or home environments.

o **Adult Respiratory Failure.** Researchers in four SCORs have implemented 18 separate studies on the biochemical, immunologic and physiologic mechanisms of acute lung injury and repair. Results from these studies will improve the diagnosis, manangement, and prevention of adult respiratory distress syndrome.

o **Cardiopulmonary Disorders During Sleep.** Three SCORs have initiated 13 projects including both basic and clinical research relevant to the pathogenesis, prevention, diagnosis, and management of cardiopulmonary disorders--such as sleep apnea syndrome--during sleep.

o **Cystic Fibrosis.** Research in three SCORs emphasizes the exploration of basic mechanisms underlying cystic fibrosis. Over 10 individual projects are elaborating new hypotheses and generating innovative strategies for approaching clinical issues.

The President's FY 91 budget request for the NHLBI includes $86.3 million for the support of 54 SCORs. There are essentially no new funds available for this program in the President's request. Moreover, since 1988, the SCOR program has received a 3% decrease in funds although the Institute, by mandate, initiated 2 new programs: Cardiopulmonary Disorders During Sleep and Cystic Fibrosis.

The serious imbalance in research mechanisms has severely compromised this essential program. A review of its funding history during the last decade as compared to Research Projects clearly indicates the critical nature of the funding situation:

o Since 1981 SCOR program activity increased by 6% with an overall increase in funding of 25%, $63.6 million in 1981 to $86.3 million in 1990. During this period, the average cost of each SCOR increased 22%. This funding picture changes dramatically when a review is made of the percentage total of the extramural program activity for SCORs--SCOR funding levels in 1990 represent a 31% decrease in the percentage share of the Institute's extramural budget.

o In the same period of time, Research Project activity increased 15%--2356 grants to 2799 grants. Funding was increased 57% from $288.8 million in 1981 to $670.3 milliom in 1990, with the average cost of a grant increasing 50%. Moreover, the funding increases represent a 15% increase in the percentage share of the Institute's extramural budget.

As a consequence of these changes in distribution and the resulting steady decline in funding, the Research Centers mechanism has become severely compromised. The situation is further compounded by annual reductions in individual SCOR awards. Routine "downward negotiations"--reductions made in grant levels from the approved levels--have been made to address the shortfall in funds available for this research mechanism. Such "downward negotiations" have increased by 45% since 1988. In FY 90, individual SCOR programs are receiving a 20% reduction in their annual budget. Moreover, this reduction is approximately twice the level received by competing research project grants.

The budgetary dilemma currently faced by the SCOR program is further complicated by the system of rotational competitive renewals. Center awards are made for a five year period. During the renewal process, significant budgetary growth is anticipated to counter previous inflation and to allow for adequate resources throughout the period of the award. In FY 91, three SCOR programs will be renewed and in FY 92 and additional five programs will be renewed including four within the Division of Lung Diseases.

The ALA/ATS strongly support this research mechanism and urge the Subcommittee to initiate action to resolve the critical funding situation. Several steps are necessary to restore and rebuild the SCOR program:

- In FY 91 an additional $18 million should be provided for the Research Centers mechanism to restore awards to their approved levels and provide sufficient funding for the programs undergoing competitive renewal.
- To expand the program, essentially stable during the last decade, $24 million should be provided to begin new SCOR programs. Areas identified where the SCOR mechanism would be useful include vascular biology and sudden death.

In conclusion, Mr. Chairman, the SCOR program within the NHLBI has made an invaluable contribution to our understanding of lung disease--its diagnosis, management and prevention. A continued decline in this research mechanism will result in the slowdown of direct application of research findings and subsequent benefits to patients.

Thank you for this opportunity to comment.

STATEMENT OF ROBERT J. SCHWEITZER, PRESIDENT, AMERICAN CANCER SOCIETY

Senator ADAMS. Our next witness is Dr. Robert Schweitzer, president of the American Cancer Society.

Doctor, welcome.

Dr. SCHWEITZER. Thank you, Mr. Chairman. I appreciate the opportunity to testify in behalf of funding of the NCI bypass budget for the fiscal year 1991. I am Dr. Robert Schweitzer, president of the American Cancer Society. I am a surgical oncologist and professor of surgery at the University of California at Davis and associate clinical professor of surgery at University of California at San Francisco.

Each year, the American Cancer Society recommends to the Congress a citizens' budget figure for the National Cancer Institute for the coming year. The battle against cancer has reached a crucial stage. While appropriations have been increasing in recent years, they have not been able to keep up with the potential momentum in cancer research progress.

The American Cancer Society believes that 1991 will be a year of dramatic, significant advances against cancer. Because of this, we are recommending a citizens' budget of $2.41 billion for the National Cancer Institute for the fiscal year 1991. This figure represents a significant increase over the President's budget for 1991, but we believe it is fully justified and realistic, considering the opportunities and the potential. We are convinced it is an amount that will be well spent. Also, we believe it is a small investment, promising giant returns in the cancer battle, which is costing the Federal Treasury more than $70 billion each year in lost wages, increasing the cost of treatment, lost tax revenue, and human suffering.

Research, both basic and clinical, remains a key element in the progress against cancer. We believe in the need to increase the percentage of approved research grants, which are actually funded. A key reason for the American Cancer Society's support of the NCI director's bypass budget for 1991, is to achieve our recommendation of 50-percent funding of approved research grants, as compared with the administration's fiscal year 1991 request, which would only fund 27 percent of approved research grants.

Inevitably, a tremendous number of good, important ideas are not being followed up as a result of the current, low level of research funding. And it is difficult for a group of scientists to predict exactly the source of the best ideas, and the clue to the critical information which might move us quantum leaps ahead could be lying among the grants that we have not had the money to fund.

We have made significant progress against cancer, and this is clearly tracked by the implementation of the national cancer program. We have made dramatic progress against cancer in the under 65, for example, testicular cancer, Hodgkins, leukemia, children's cancer, uterus cancer, bladder, stomach, pancreas and breast, but our progress has not been so positive in the elderly.

PREPARED STATEMENT

In conclusion, we have reviewed the NCI public documents, talked to our colleagues at the Institute and asked a number of questions. We have a tremendous respect for the NCI leadership, and believe the 1991 bypass budget is an accurate reflection of the needs for next year's opportunities.

Thank you for this opportunity. I would like to submit my written statement for the record.

Senator ADAMS. Without objection, your entire, written statement will appear in the record as given.

[The statement follows:]

STATEMENT OF ROBERT J. SCHWEITZER

The American Cancer Society is pleased to present a proposal for FY 1991 for the National Cancer Institute "Citizen's Budget" on behalf of the American Cancer Society, the world's largest voluntary health agency -- over 2 million active volunteers.

I am Dr. Robert J. Schweitzer, president of the American Cancer Society. I am a surgical oncologist and an associate clinical professor of surgery at the University of California School of Medicine in San Francisco.

Each year the American Cancer Society (ACS) recommends to the Congress a "Citizen's Budget" figure for the National Cancer Institute for the coming fiscal year. Traditionally, this figure has represented the best judgement of the American Cancer Society regarding that portion of our country's national resources which we believe our government should dedicate to the battle against cancer.

Our nearly two and one-half million volunteers serve the people of this nation in every state, county and community, at no cost to the government. All American Cancer Society funds are raised privately from the American people. The American Cancer Society receives no government funds of any kind.

Support of cancer research is one of our major activities. In 1989, the American Cancer Society provided nearly $90 million in support of investigator-initiated, peer reviewed research. Additionally, we allocated almost $62 million of our voluntarily donated funds to public education; approximately $70 million to patient and community services; and almost $31 million to professional education.

This year, the Administration budget requests $1,533,252,000 for the cancer (non-AIDS) portion of the NCI appropriation, with an additional $160.8 million for AIDS --- for a total proposed NCI level of $1,694,059,000.

The battle against cancer has reached a crucial stage. While appropriations have been increasing in recent years, they have not been able to keep up with the potential momentum in cancer research progress.

The American Cancer Society believes that FY '91 will be the year of dramatic, significant advances against cancer. Because of this, we are recommending a "Citizen's Budget" of $2.410 billion for NCI for FY '91. This figure represents a significant increase over the President's budget for FY '91, but we believe it is fully justified and realistic considering the opportunities and the potential. We are convinced it is an amount that will be well spent. Also, we believe it is a small investment promising giant returns in the cancer battle which is costing the federal treasury more than $70 billion each year in lost wages, increasing cost of treatment, lost tax revenue, and human suffering.

Research, both basic and clinical remains the key element in progress against cancer. We believe that the most compelling argument for higher funding is the urgent need to increase the percentage of approved research grants which are actually funded. A key reason for the American Cancer Society's support of the NCI Directors' Bypass budget for FY '91 is to achieve our recommendation of 50% funding of approved research grants, as compared with the Administration's FY '91 request which would fund only 27% of the approved research grants.

Inevitably, a tremendous number of good, important ideas are not being followed up as a result of the current low level of research funding. It is difficult for a group of scientists, reviewing research applications, to predict exactly the source of the best ideas. The clue to the critical information which might move us quantum leaps ahead could be lying among the grants we have not had the money to fund.

Undeniably, exciting, significant progress is being made against cancer -- and that progress is clearly tracked from implementation of the National Cancer Program. But definable progress also reveals where the next generation of challenges are: we've made dramatic progress against cancer in people under sixty-five years of age -- testicular cancer, Hodgkins disease, leukemia, cancer in children under 15 years, uterus, bladder, stomach - even pancreas and breast cancer. But our progress has not been so positive in the elderly. Cancer in the older population requires renewed emphasis and more vigorous attack.

The one cancer that continues to cause more deaths than all others is lung cancer -- a preventable cancer. The entire slate of man's effort against cancer would show great achievement and encouragement were it not for the distorted picture presented by this, which has the highest incidence, yet is most preventable of all cancers.

An appropriation of $2.410 billion would allow the NCI to increase efforts to determine cancer detection and survival for our minority populations such as blacks, Hispanics and Native Americans; encourage the expansion of cancer prevention and awareness programs conducted by historically black colleges and universities; and increase support for NIH's scholarship programs that are designed to attract students from minority institutions to pursue careers in the biomedical sciences.

The aged would also receive attention through the expansion of efforts to determine survival and mortality differences between people over 65 compared to those under the age of 65. Efforts will continue to be made to work cooperatively with the National Institute on Aging by focusing on prevention, early diagnosis and treatment for people over 65.

The Women's Cancer Detection Program would be expanded to enhance outreach activities relative to mammography and the Pap test.

Biomedical programs would be expanded such as 1) the Diagnosis Program, which would accelerate the transfer of new diagnostic approaches into clinical application; 2) the Drug Development programs, particulary in natural products chemistry research and screening efforts in preclinical drug development; and 3) the Vaccine Research Program which would emphasize cancer-related vaccine research, viral research, specific antigens, and special cell surface epitopes that elicit such host defense cells.

We have reviewed NCI public documents, talked to our colleagues at the Institute, and asked a lot of questions. We have tremendous respect for NCI leadership, and believe the 1991 bypass budget is an accurate reflection of the needs for next year's opportunities.

Thank you for the privilege of presenting the testimony of the American Cancer Society on the FY '91 National Cancer Institute appropriation.

Senator **Adams**. Doctor, I have just one question. Do you believe we are doing enough to get what we have learned in cancer prevention, detection, and treatment, out into the field where it can be put to use? You are sort of in the middle between the research groups and the ones that are doing this, and you are in the field yourself, so that is the reason that I have asked you this question.

Dr. **Schweitzer**. I do believe that we are trying to do enough. I believe there is room for improvement, and we must continue to fund these various programs, because many of the programs that we did not have a chance to enumerate are not necessarily research programs. They are programs that deal with the actual cancer control. And real attempts are being made to bring the basic research to the bedside as quickly as possible, and that is so essential.

Senator **Adams**. Thank you, Doctor, for being with us.

STATEMENT OF ROBERT W. DAY, FRED HUTCHINSON CANCER RESEARCH CENTER

Senator **Adams**. Our next witness is Dr. Robert Day, the Fred Hutchinson Cancer Research Center.

Dr. Day, it is a pleasure to see you this morning.

Dr. **Day**. Senator, I am delighted to be here.

Senator **Adams**. Dr. Day is from Seattle and I have known him a long time, and I taught his wife Sunday school, so I figure that I have a chance to shake hands with him this morning.

Dr. **Day**. That made an indelible impression in her, Senator. I want you to know I appreciate it personally. I am delighted to be here.

Senator **Adams**. Welcome. We are very pleased to see you and I want you to know that the people of Seattle are grateful that we have such a center in our city. It has been helpful to my mother and to many others through the years, and we appreciate it.

Dr. **Day**. Thank you. We appreciate your support and that of your colleagues.

I have submitted a written statement which I would like to briefly abstract in my remarks.

Senator **Adams**. Without objection, your entire statement will appear in the record as though given.

Dr. **Day**. This is a critical year for biomedical research. I am, of course, particularly concerned about cancer research, but biomedical research, in total, is having difficulty and the difficulty is very simply summed up in that is underfunded. We are severely underfunded in training, in construction, in supportive centers, in supportive research grants and contracts.

For example, this year, approximately one in four meritorious research applications will be funded. Now, this is the worse that I can remember in my many years as a scientific investigator and administrator of scientific institutions.

So, I would ask the committee, with all urgency and speed, to increase in a major way, the appropriation to the National Institutes of Health. The recommendations you have heard from a number of various groups, including the group we belong to, the Association of American Cancer Institutes. Dr. Salmon will be testifying shortly.

And I would like to urge that we have an increase, and the increase requested this year in the budget committee is $1.4 billion. If we have an increase of that sort, the sorts of problems we are hearing about from everyone will be very quickly solved.

There are three areas in particular that I would like to mention. One is the biotechnology industry. This is a very important new industry in our area. As you know, there are several companies that have started from the cancer center; more will be starting. And the reason that the biotechnology industry in this country has prospered is because of basic research conducted at the National Institutes of Health. We have to continue that, or I am afraid we will lose our lead as the leading country in the world in biotechnology.

The other areas are training and construction and prevention. And just a word about prevention, which is a very major program at the Hutchinson Center. Here again, we have had basically no increase in support and yet we have many promising leads that we should be following.

PREPARED STATEMENT

So, in summary, I would just say again, we are underfunded. The problems that you and your colleagues are hearing and will continue to hear relate to that underfunding. We need a major increase in support this year.

Thank you.

[The statement follows:]

STATEMENT OF ROBERT W. DAY

Mr. Chairman and Members of the Committee, I am Dr. Robert W. Day, Director of the Fred Hutchinson Cancer Research Center ("Hutchinson Center") in Seattle, Washington. The Hutchinson Center is one of the comprehensive cancer centers recognized by the National Cancer Institute. The Center, incorporated in 1972 and began operations in 1975. It is well recognized nationally and internationally for pioneering research in the development of bone marrow transplantation for the treatment of malignancies, for its strengths in basic sciences, particularly molecular biology, and for its extensive activities in cancer prevention and cancer control research.

Federal Fiscal Year 1991 represents a major opportunity for the Congress to address problems that have accumulated over the past several years with Federal support for biomedical research.

During the 1980's the budget of the National Institutes grew an average of 3.6% a year in constant dollars. However, the inflation in costs of performing medical research grew as well and the growth of our research budget has not kept pace with inflation. Further, emerging technologies, exploration of promising new and important areas of biological research, and the gradually expanding capacity of the Nation to perform biomedical research have contributed to what is now a serious shortfall in Federal support.

This year the Hutchinson Center is experiencing the most stringent conditions for the performance of externally supported research that I can recall. Only one in four meritorious new grants is being funded this year. Noncompeting renewals of existing grants are being reduced by an average of 10%, compounded upon decreases of support in prior years of 9 and 11%. Those fortunate scientists to have new awards are seeing their budgets reduced by approximately 20% from the carefully peer reviewed, and in most instances already reduced budgets that are considered the minimum to do the scientific work proposed.

Over the past decade there has been a major erosion in support for training, for construction, and for new technology. The infrastructure of the research enterprise in this country is seriously threatened. We have had virtually no construction money or support for renovation or for new technology since 1986, except for small programs to address top priority programs--AIDS construction, equipment and instrumentation; and, animal facilities.

Training support has been reduced. In the 1970's, 13% of the overall Budget was directed to research training. In 1991, less than 5% will be spent on training. When coupled with the current, very bleak prospects for support during a research career we are on the threshold of losing an entire generation of biomedical investigators.

Contrast this with the promise of immediate as well as future benefits from expanding and strengthening our research enterprise. I can speak best for the field of cancer research. Developments in the basic knowledge of cells and cellular mechanisms is beginning to see fruition in practical applications in prevention, diagnosis and treatment. Testimony provided to you by the Institutes and by other witnesses details the importance of growth factors in the treatment of various kinds of cancers, advances in early diagnosis, and clinical trials demonstrating better ways of managing cancers to prolong survival. Literally an entire storehouse of new and emerging information about the cell and the controls of growth and differentiation will, if support is appropriate and forthcoming, rapidly find its way into new and improved applications in the clinical setting.

We are learning more about ways to prevent cancer. Much of this is based on understanding better what causes cancer. Investigators at the Hutchinson Center have a major interest in determining whether or not reductions in dietary fat will as predicted result in reductions in a number of cancers that afflict women, notably breast, ovary, colon and endometrial. In addition, a trial which reduces fat will also be beneficial in reducing heart disease. A number of groups around the country are interested in participating in a multicenter trial of this sort. Unfortunately, although the design has received strong support through peer review, budget shortfalls have thus far prevented beginning such a major study which will have important implications for how we as a nation can improve our health and reduce a number of very consequential diseases.

Major improvements in our health have been brought about through research. Other improvements lie ahead if we maintain the commitment to research. A long life as free of disease as possible is something I believe almost all of us strive for. What we lack is the knowledge of how to reach this objective.

The last decade has seen, in addition to major improvements in our knowledge and our ability to manage a variety of diseases, the growth of a new industry in the United States. In biotechnology we are first and foremost. It is the knowledge that has accumulated from the public investment in biomedical research that is the foundation of this industry. In Seattle, for example, several companies were started successfully by scientists at the Hutchinson Center. Steady growth of new biotechnology companies based upon the work of the scientific staff of the Hutchinson Center has characterized the past several years. Support of the National Institutes of Health has been vital in developing and maintaining this new industry with the United States at the forefront. We could lose this quickly unless we maintain a vigorous research base from which potential applications are derived. To receive the benefits of basic studies it is necessary to have the applied research and development and ultimately the products that influence our health. We must maintain a large, well-supported and well-equipped cadre of excellent scientists whose discoveries will continue to fuel the industry.

I support the proposal of the Ad Hoc Group for Medical Research of $1.4 billion above the 1991 President's Budget Request as the minimum increase for the NIH. This is one-third of one percent of the Defense Appropriation. It will solve many of the problems in the support of research. Since only one in four meritorious research proposals is currently supported there is room to expand the research base with support of excellent science which currently goes unfunded. The research system thus has the capacity to perform well with such an increase. Additional dollars will aid in training a new generation of scientists and will provide continuing evidence that as a national priority support of biomedical research remains one of the highest items.

Many of the problems mentioned above are the result of severe underfunding for biomedical research through the National Institutes of Health. And while the proposal to increase support to the Institutes overall by $1.4 billion in FY 1991 will benefit all aspects of the Institutes work, there are two very specific areas to which I wish to address further comments.

The Cancer Centers Program of the National Cancer Institute is severely impacted by a budget shortfall. For example, in FY 1988 one major cancer center was phased out. Fifty-eight cancer centers remained, and in 1989 four of those could not be supported further from the cancer centers core grant budget allocation. In the current fiscal year there remains a very serious problem. Seventeen of the remaining centers are in the cycle for a competitive renewal. There is one new center application. How NCI will solve the budget problem at this stage I do not know. However, we have already been told that our core grant will be reduced again, although the specific amount of reduction has not as yet been announced. Without question some of the 17 centers up for competitive renewal will probably not be supported.

The cancer centers provide the site for at least one-half of the supported research of the National Cancer Program. The comprehensive and clinical centers are widely distributed throughout the country and lead in all areas of cancer research. In addition, these local institutions utilize their own resources and provide considerable support to improving standards and procedures for patient care, for specific efforts directed at undeserved populations, and in the promotion of improved public understanding about causes of cancer and how cancer may be prevented. Based upon the fact that cancer centers not receiving support in recent years have in the main been judged meritorious, an increase in the appropriation for the cancer centers is badly needed.

The National Cancer Institute under the National Cancer Act is empowered to present a By-Pass Budget which goes directly to the President. For FY 1991 the By-Pass Budget requests an increase of approximately $40 million over the slightly more than $100 million in the Administration's request for the cancer centers item. I urge the members of the Subcommittee to take into consideration the By-Pass Budget recommendation for the cancer centers in developing your budget for the NCI.

Further, the National Cancer Act specifies and provides support for cancer control. I have referenced already the importance of research testing the effectiveness of reducing fat in the diet upon reducing a number of cancers which are very important in women. This is a trial that we must pursue. In order to do so, however, new, additional funding for cancer prevention and control will be required. Additionally, there are a number of other very promising approaches to screening, early diagnosis and prevention of cancer which require specific support through enhancement of the budget available in cancer control. Again, the Bypass Budget recommends $157 million for cancer control for FY 1991, a figure which derives from careful review within NCI of needs which can be met by sound research to be supported in that amount.

In closing, I wish to thank you for this opportunity to present these views. I would stress again that the needs of biomedical research in this country are great, and will not be attended to without a very major increase in Federal support to the National Institutes of Health. The benefits of such an increase I believe are apparent. Those benefits include improvements in our health and well being as well as continued growth of a vigorous new industry in which the United States remains the leader. But we must now attend to developing a new cadre of scientists through better training support, by improvements in our laboratories, facilities and equipment to remain at the front rank scientifically, and thorough support of a variety of research essential to restoring vigor in our biomedical research establishment.

This concludes my formal statement, I will be happy to answer any questions you may have. Thank you.

Senator **Adams**. Thank you very much, Dr. Day.

You mentioned one thing that I do want to question you about. What do you think are the program priorities that we should be addressing in cancer prevention and control? I would like a little something on that that would give me some idea, because we are going to be in a problem before this committee, doing some picking and choosing. I am not saying that all of us support that, but that will be a problem. Can you give me some idea?

Dr. **Day**. I would be happy to. I believe our biggest, unknown area right now, in cancer prevention, is the role of diet, diet and nutrition. We have very good reason to believe that it is quite important. There is very good evidence to that affect. What we need to do is test, in the human population, whether major reductions, particularly in fat in the diet, will reduce some of our cancers. That is the only way we can get that answer. But the promise is so great that we really need to pursue those leads right now.

Senator **Adams**. Thank you very much, Doctor. We appreciate your testimony this morning.

STATEMENT OF WILLIAM L. DEWEY, PRESIDENT, FEDERATION OF AMERICAN SOCIETIES FOR EXPERIMENTAL BIOLOGY

Senator **Adams**. Our next witness is Dr. William Dewey, president of the Federation of American Societies for Experimental Biology.

Welcome, Dr. Dewey. It is a pleasure to have you here with us this morning.

Dr. **Dewey**. Thank you very much. I appreciate the opportunity to be here. I am the associate provost for research and graduate affairs of Virginia Commonwealth University, and president of FASEB, as you have mentioned.

We have submitted written testimony, which is cosponsored, by the way, by the American Society of Microbiology, since they were not able to be here, and their 36,000 members. So our testimony represents about 70,000 people, sir.

Senator **Adams**. The testimony, as you have outlined it will, without objection, be included in full in the record.

Dr. **Dewey**. Thank you very much.

First, I would like to thank you and your colleagues for the continued support for research for National Institutes of Health and the Alcohol, Drug Abuse, and Mental Health Administration, both of which are so important for the health of our society. However, we are very concerned as the previous person who testified said, that the amount of funding for research at this time is a very critical issue.

Three years ago there were 6,400 new and competing grants that were awarded, and there were 5,300 a year ago, and at the present time it is down to 4,600. We know that the proposal from the administration is to increase that to 5,000.

What is happening out in the community—these grants are not only being funded in fewer numbers, but there is getting to be an expected downward negotiation, where after the study section has reviewed it and made its recommendations, grants are being cut 10 to 15 percent.

We feel that both of these issues are extremely important. First of all because of our scientists out there who are having an interruption in their work. It is again getting to be expected that certain scientists will have a period when they are not funded and their laboratory has to close down and then start over again. That is not an efficient way to run a laboratory. It is not in the best interest of this country for that to happen.

We would like to propose, then, that there would be for next year, enough money appropriated by Congress, that we could fully fund 30 percent of the grants which are submitted and are proved, 30 percent of the approved grants. There are problems such as Alzheimer's disease and cancer, as some of the previous people have spoken about, AIDS, drug dependence, mental health, et cetera, for which we can make important contributions and are making important contributions.

To be personal, I have a son who is a diabetic, and I believe strongly that we can cure diabetes if we have the funds to do it. We are making progress. There are many other diseases in the same light, where advances are being made which directly affect the health of the American citizens today. We need the money to carry out this research, both basic and clinical, to bring these things about.

The other thing we need is trainees, people in graduate school and other folks who are considering their livelihood, look at scientists who write a grant for 2 months. It gets approved with a good priority score and everything comes back as positive, but yet, it is not funded. It happens again and again. There has to be a time when these people will see that those efforts come to fruition and they are funded for their research.

As I say, with only 24 percent of the approved grants funded, that is an awful lot of folks who get a good score and do not get the money which they need to carry out their research. People are leaving the fields of biomedical research, and we need the influx of new ideas. This is absolutely essential.

PREPARED STATEMENT

It seems to me that if the cost of medical expenses to this Nation, the medical burden is $500 billion, it would be well worthwhile, as the ad hoc group has proposed to spend $9 million at NIH—$9 billion, excuse me, at NIH and also $1.1 billion at ADAMHA to cure these diseases.

I thank you for the opportunity for this testimony, sir.

[The statement follows:]

STATEMENT OF WILLIAM L. DEWEY

Mr. Chairman and Members of the Subcommittee:

I appreciate the opportunity to testify before your Subcommittee. I am Dr. William L. Dewey, associate provost for research and graduate studies at Virginia Commonwealth University. I appear before you today as President of the Federation of American Societies for Experimental Biology (FASEB).

The Federation consists of seven scientific societies with a combined membership of almost 30,000 biomedical researchers. The members of the Federated Societies represent every major research, educational and clinical institution in the United States. FASEB has counted 116 Nobel Laureates from among its members since the organization was founded in 1912.

The members of our societies are grateful to your Subcommittee for its strong commitment to the National Institutes of Health (NIH) and the Alcohol, Drug Abuse and Mental Health Administration (ADAMHA). Your solid support for these agencies over many decades has been critical to the progress made against disease.

Both NIH and ADAMHA have excellent research programs led by government scientists working in laboratories in the Washington area and elsewhere. However, the major portion of the two agencies' budgets fund research project grants at academic and research institutions throughout the country. The nongovernment scientists who perform this "extramural" research are equally distinguished. They obtain government grants only after rigorous scientific review of their proposals and their records of productivity.

Funding for extramural research has been growing at too slow a rate to take advantage of the many research leads available, or even to sustain the current level of discovery in America's laboratories. There has been a severe drop in the number of new and competing research project grants which represent the cutting edge of research and are at the heart of NIH's program. Scientists are deeply concerned that without the assurance of a sufficient number of new awards for research, promising young investigators are now turning to other careers, depriving the nation of future scientific leadership and economic competitiveness. And because so much of our research is based in academic institutions, the fabric of the biomedical educational system is weakened.

The recent history of support for NIH new and competing grants illustrates the problems we face. In 1987 Congress funded more than 6,400 of these grants. But by 1989, the number had been reduced to some 5,300 and in the current fiscal year (1990) it is expected to fall to 4,600. The rate at which approved grants are funded has dropped from about 38 percent in fiscal 1987 to an estimated 24 percent in the fiscal year ending next September 30.

Because of this year's tight funding, NIH will make cuts of 12 to 13 percent in each grant in order to fund as many researchers as possible. These cuts, called "downward negotiations," are damaging because they ignore the recommendations of scientific review panels, reduce the scope of the proposed research, and frequently make it impossible to do necessary research.

The major effect of these cutbacks is to deny biomedical research full input from the best researchers, our most valuable resource. When the grant budget is cut, the effort itself must be cut. There is no "fat" in the research projects.

The Administration's budget proposal for 1991 continues the fiscal straightjacket imposed on NIH. While the President proposes to increase the number of new and competing grants to 5,095, each award would be cut by about 14 percent. Noncompeting continuation grants would suffer reductions of about 10 percent.

The Administration's approach will seriously damage biomedical research at a time when diseases such as AIDS, Alzheimer's, cancer and drug addiction, pose major health, social and economic problems for the nation. These afflictions require a long-term commitment from scientists funded by NIH and ADAMHA. The key to success in these efforts will continue to be competing research project grants which are awarded to investigators whose ideas are most likely to produce medical breakthroughs. In order to conquer these diseases, we need the best ideas from the nation's best scientists.

The Federation believes the Administration's budget requires major revisions. For NIH, we recommend restoration of full funding for both new research project grants and noncompeting continuations. We also urge that Congress provide sufficient funds to support 30 percent of new and competing grant applications, raising the number of these awards to about 6,000. This will expand the opportunities for both young scientists and established investigators. All told, NIH would fund 21,344 grants.

Our recommendations, which were developed in cooperation with the Ad Hoc Group for Medical Research Funding, also include funds to support 12,020 research trainees, an increase of 225 over FY 90, as well as additional funds for other proposals, including one to improve NIH intramural facilities.

Our recommendations total a little over $9 billion. They would sustain programs at their current services levels and allow for some growth in key areas.

For ADAMHA, we cannot accept the Administration's proposal to decrease the number of research project grants from a level of almost 900 in fiscal FY 1990 to only 604 (a 20 percent award rate) in the coming fiscal year. This would be moving in the wrong direction at a time when research is on the threshold of major advances in ameliorating mental and addictive disorders.

Our proposal would provide ADAMHA with almost 1,200 competing grants, a 40 percent award rate. This would include an additional 83 awards for the National Institute on Drug Abuse. We also provide for growth in the number of centers and investment in training to reduce the shortage of clinical investigators. These physician-scientists are needed to strengthen research efforts in aging, alcoholism, schizophrenia, drug abuse and disorders of children and adolescents.

Sickness and disease take an enormous physical, social and economic toll on the lives of our people. National health care expenditures in 1987 totaled $500 billion and undoubtedly are much higher today. The funds we request for NIH and ADAMHA, which will help to reduce these costs, amount to less than two percent of the nation's health care bill. Can't we afford to spend $9 billion to reduce the $500 billion medical burden we carry on our shoulders? The answer should be a resounding "yes."

We have never been better positioned to make progress against the killers and cripplers of humankind. We are unlocking the secrets of life and of disease. We are developing important new therapies which will help us to conquer afflictions both old and new and to extend life. As the world steps back from confrontation, the United States should begin to devote more of its resources to improving the health of its people. Biomedical research is the key to achieving this goal and is deserving of your increased support. We urge the adoption of our proposals.

Senator ADAMS. Dr. Dewey, you sit in a particular position where you probably have more information than anyone else, so I am going to ask you this question. If you want to submit it for the record, that is fine, too. But would you comment to me on, if you make additional grants or more grants in fiscal year 1991, will it encourage more young people to pursue careers in science?

You talked about the problem of connection between funding grants and maintaining our young people in the research facilities. Can you give me any idea of either numbers or how you wish to best express the connection between funding these grants and keeping people in the science programs?

Dr. DEWEY. Sure. I would like to tell you, and I would like to also submit it, if possible, sir.

The specific point that I was referring to is students who have decided to come into basic research often will see their mentor, their faculty advisor, going through these kinds of problems and decide that that is not the way they want to spend their life, and change their career. Many of them go to other worthwhile professions, I will admit: to medicine, to dental, to some professional school, but will not stay in basic research. And that is one of the concerns.

The other concern is just the demographics, that the number of people coming into science that are coming out of college has been decreasing over the years. It hit a peak in the early 1980's, and now it has been decreasing, with the number going into business and other type areas is escalating quite rapidly.

How the number of grants affects that latter point is not as clear as the first point: that people are changing for basic research.

And to cure these diseases, we need more basic work done, and more clinical work done. It is a continuum. We cannot have one without the other, sir. We need both.

Senator **Adams**. Thank you very much, Doctor, and thank you for your testimony.

STATEMENT OF SYDNEY E. SALMON, PRESIDENT, ASSOCIATION OF AMERICAN CANCER INSTITUTES

Senator **Adams**. Our next witness this morning will be Dr. Sydney Salmon, president of the Association of American Cancer Institutes. If I have mispronounced it, I apologize in advance. I have used it both ways.

Dr. **Salmon**. Senator Adams and committee members, I am Dr. Sydney Salmon, director of the University of Arizona's Comprehensive Cancer Center and president of the Association of American Cancer Institutes, or AACI.

In my presentation, I will focus on elements from my written statement on the Institute of Medicine's report on cancer centers and the administration's proposed NCI budget for centers for fiscal year 1991.

You recall the request made by the Congress in the appropriations process 2 years ago, in response to which, the NIH commissioned the Institute of Medicine, or IOM, to conduct a major study on the NCI's cancer centers program. The report strongly supports the centers and emphasized their central role in our Nation's cancer research program, both basic and clinical research, and prevention and control.

It also made a series of recommendations considered essential for continued viability of the cancer centers program. The NCI director took the IOM recommendations on program organization quite seriously.

Unfortunately, the administration has not responded to the critical budgetary needs as stressed by the Institute of Medicine. During the past year, deep cuts were made in the centers' funding. Additionally, good centers lost their funding, above and beyond those lost in the prior 2 years.

For fiscal year 1991, the problem is even worse, with the centers' budget increased by only $159,000 or two-tenths of 1 percent. This is really a further cut after inflation, and will not permit restoration of defunded centers. This is despite the IOM's calling for immediate steps to avert a crisis.

The AACI believes that the administration's language on page 145 of the budget justification is incorrect and misleading, by implying that their proposed level of funding will avoid a further decline in the number of cancer centers and be sufficient to ensure that the critical role of cancer centers is maintained and fully realized in the future.

Your committee must recognize that the administration's budget, if enacted, will result either in a potential defunding of 10 centers, or require massive cuts averaging 30 percent in the budgets of all cancer centers.

Note that the President's budget proposes a 4.7-percent increase for the NIH overall, 3.7 percent for the NCI and 0.2 percent for cancer centers. Is this an appropriate response to the IOM report?

The answer is clearly no. We call upon the Appropriations Committee to correct this serious problem.

The AACI fully supports the NCI's bypass budget with a $36 million addition to the cancer centers program. But we would emphasize that even one-half that amount would keep the program alive, albeit not completely healthy. On the other hand, the administration budget puts the centers program in jeopardy of total collapse.

PREPARED STATEMENT

Mr. Chairman, the cancer centers of our Nation as represented by the AACI, stand ready to continue our leadership for the American people, and cancer research and care, and hope that this effort can be maintained with funding at a critically needed level.

I will be pleased to answer any questions, sir.

[The statement follows:]

STATEMENT OF SYDNEY E. SALMON

Mr. Chairman and Members of the Committee, thank you for the opportunity to appear before you on behalf of funding for the National Cancer Institute, and specifically for the cancer centers of our Nation, in the FY 1991 appropriations process.

I am Dr. Sydney E. Salmon, Director of the University of Arizona Cancer Center in Tucson, Arizona, and President of the Association of American Cancer Institutes (AACI).

Mr. Chairman, my statement will be short because I know the time constraints under which you are working.

I have good news to report to you, some bad news, and a series of recommendations.

First, the good news:

Research Advances:

. Within the past year, important advances in basic and clinical research have occurred in our nation's cancer centers. Examples at the basic research level include the identification of tumor suppressor genes and/or chromosomes in cancer cells that exhibit loss of a tumor suppression in cancers of the colon, prostate and melanoma. These findings not only provide new understanding of cancer as a disease, but also suggest potential new diagnostic tests to identify premalignant stages of tumors and lead to the development of new prevention strategies.

. There have also been several important advances at the clinical level. One is the discovery and use of chemosensitizers that can reverse resistance to anticancer drugs and make cancers such as malignant lymphoma and myeloma regain drug sensitivity with the patients going back into remission again.

We believe that these observations may lead to a new era in cancer treatment wherein resistance can be blocked even before it develops in the patient and increase the effectiveness of existing anticancer drugs and lead to the development of new ones.

. Clinical research on bone marrow growth factors, such as the white cell stimulating hormones, has shown sufficient benefit that the FDA will be reviewing product licensing applications this year for use of these drugs to reduce or eliminate low blood counts as side effects of chemotherapy and permit more effective chemotherapy to be used.

IOM Report: You will recall, I am sure, the request made by the Congress in the appropriations process two years ago that was made to the National Institutes of Health to have the Institute of Medicine do a major study of the situation regarding funding for cancer centers, and the organization within the National Cancer Institute to better assist the cancer centers in our mission.

The good news is that the report was made on time, it was very strongly supportive of cancer centers, and made a series of recommendations to improve the situation of the cancer centers at the NCI. It clearly emphasized the importance of the cancer centers in the entire national cancer research effort.

I am also pleased to report to you that the Director and staff at the NCI have taken the recommendations very seriously and have made a very strong good faith effort to deal with them, especially those dealing with the organization within the NCI as it relates to cancer centers.

The bad news is that despite the fact that the Director and staff of appeared to take the report seriously, the Administration has not been able to respond to budgetary implications. During the past year, very deep cuts (in some cases approaching 20% below peer-reviewed and agreed-upon levels) were made in centers funding. For FY 91 the Administration's budget totally fails to respond to the budgetary implications in the IOM report that was developed last year on authorization of the Senate. Recall that the IOM report stated that immediate steps must be taken to avert a crisis -- those steps have not been taken. The body of the report indicated that the inadequacy of the centers' budget was resulting in the loss of critically needed resources in our nation's fight against cancer, and indicated that the current budgetary trend would result in the loss of at least 10 additional regional cancer centers from the NCI program. You will note in the Administration budget for FY 91 that there is a call for an increase in the budget for cancer centers of only $159,000. This represents only a 1/5 of 1% increase in the budget and in fact represents a cut in the cancer centers' budget when corrected for inflation. The AACI therefore believes that the Administration's language on page 145 of the budget is simply incorrect and misleading. It states, and I quote:

"This request for an increase in the FY 1991 budget will avoid a further decline in the number of centers throughout the nation which receive NCI core grant support, and will permit a level of funding necessary to ensure that the critical role of cancer centers in the National Cancer Program is maintained and fully realized in the future."

It is important that the members of your committee recognize that the Administration's proposed budget for our nation's cancer centers, if enacted, will result in either a defunding of 10 additional centers if surviving centers are to receive adequate budgets to operate, or would require massive cuts in the budgets of all centers. If the latter course is followed by the NCI, then the centers will suffer an average 30% cut in their budgets. Inasmuch as the core grant budgets are overwhelmingly for personnel costs, such cuts will cause serious hardship, layoffs, and more importantly, discontinuation of key programs that are needed for the centers to be successful in their mission and to survive.

Note that the President's budget proposes a 4.7% increase for the NIH overall, and about a 3.7% increase for the NCI. Contrast that to a 0.2% increase proposed in the budget for the cancer centers. We therefore ask you, how can the Administration's budget represent a reasonable response to the IOM report? Our conclusion must be that the Administration's budget is inadequate and we call upon the Appropriations Subcommittee to correct this serious problem.

I recognize that the budget is severely constrained. Nevertheless, it is a fact that cancer centers have received a much lower percentage increase of funding than other categories in the National Cancer Institute over the last several years. This has occurred in spite of the Institute of Medicine report, and in spite of the fact that the Congress consistently has been supportive of the Cancer Centers Program in authorization and in appropriations legislative action.

To remedy this matter, we make a recommendation below. We also make a series of recommendations about improvements in funding for the NCI overall, and for research grants, training programs, and clinical research.

Before I make our recommendations, I would like to make a very important point: It is that a very large proportion of all peer-reviewed cancer research now occurs at NCI designated centers nationwide. Therefore, the issue of core support for these centers is critically important to the entire National Cancer Program.

Recommendations:

- We recommend that in addition to the President's budget, there be made available at least $12 million additional in fiscal year 1991 for the Cancer Centers Program. This would go a long way to relieving the very serious stresses over the last several years and would provide continuation of excellent centers. The NCI By-Pass Budget proposes $36 million; this recommendation would restore funds for the centers phased-out in 1989 and 1990 which are expected to resubmit in 1991; pay continuing centers at committed levels and competing centers at recommended levels; fund approximately five new centers; and fund one or more minority demonstration centers, and also enhance the number of minority and over-age-65 focused supplements. The By-Pass Budget is a budget that we support fully, but it you cannot provide the By-Pass Budget, please appropriate the $12 million that will be required to keep the Cancer Centers Program alive and healthy.

- We also recommend strong support for the other programs of the NCI, including clinical trials so vital to advances in patient care, training and education, research and construction grants.

Summary: Mr. Chairman, the cancer centers of this country, as represented by the Association of American Cancer Institutes, stand ready to do their very best to improve the lives of the American people through cancer research and care. We believe it is in the best interests of the United States population to have cancer research funded at an appropriate level, and we therefore support the By-Pass Budget as the best professional judgment of the needs in cancer research.

I would be pleased to answer any questions you may have.

Senator ADAMS. Doctor, I have a question on your ability to make up for the shortfall in Federal dollars. It has been an administration position in a number of areas, and they have pursued it, according to your testimony and other information that we have, particularly in the health area.

Have you been able to take steps as they indicate, to make up for the shortfall of Federal dollars by either private funding or other sources that are allowing you to keep your program at either the same level or to meet the needs that you have testified to for the centers?

Dr. SALMON. Senator, I think that all the centers are desperately making the effort to do that, but this is not something that is readily feasible or consistent. That is, that we all seek donations, we all seek support from other sources, but industrial contracts are usually of extremely short duration, a year or less, and they are highly project oriented, and do not fund the infrastructure of a center. They deal only with specific projects.

Similarly, donated dollars, we all seek them, but they are insufficient to make up the deficit that has occurred in the centers program.

Senator ADAMS. That last conclusion was what I wanted to be certain that I was correct about, because we will be using that in testimony and in our work as we proceed through this bill, because that is going to be a major argument so far as the Senators are concerned.

Dr. SALMON. These other sources do not provide the stability. It takes 5 or 10 years to develop a cancer center and to develop the infrastructure, and these other sources just do not provide an ongoing source for stability. Only the NIH/NCI budget for centers can provide that.

Senator ADAMS. Thank you very much, Doctor, for your testimony. We appreciate it.

STATEMENT OF KAREN ANTMAN, AMERICAN SOCIETY OF CLINICAL ONCOLOGY

Senator ADAMS. Our next witness is Dr. Karen Antman, American Society for Clinical Oncology.

Dr. ANTMAN. The American Society for Clinical Oncology would like to thank you for the privilege of appearing here today. I am Dr. Antman. I am the clinical director of a bone marrow transplant, clinical research program at Harvard Medical School.

Because of clinical trials funded 4 to 5 years ago, we have learned this year that in large, randomized trials, the most reliable kind, that chemotherapy after surgery has prevented recurrences in patients with certain stages of colon cancer. Colon cancer is the second most common cancer in the United States. An application of this knowledge could save an estimated 2,500 Americans who develop this tumor.

Additional studies have shown that chemotherapy after surgery for relatively early breast cancer could avoid relapse in an additional 4,500 women each year as well.

Our major challenge is ensuring that all of those who would benefit from these therapies, actually receive it. These advances involve investigational drugs or techniques that are not yet broadly available and ASCO, as an educational organization, has a commitment to making these available to all Americans. These are also the kinds of research that make clinical research an exciting field for young physicians.

Regarding funding for fiscal year 1991, ASCO members are aware of the constraints of the Federal budget and are particularly concerned with the spiraling cost of medical care. But in an effort to control the costs of patient care, research has become a vulnerable, and we feel, inappropriate target for cost cutting. Halfway technology is expensive but curing patients is generally cost effective.

The public's major concern is that the appropriated funds for the National Institutes of Health, improve the health of the American public, and we believe that funds expended for cancer research have had and will have a major, positive effect on the health of the American people.

We strongly support substantially increased funding for the NIH-supported biomedical research. We agree with the other speakers.

The President's proposed fiscal year 1991 budget for the National Cancer Institute provides a 3.6-percent increase for cancer research. Because of the deflation factor for biomedical research, that would actually result in a reduction of research funding.

ASCO is particularly concerned by the prospect of only a 2.5-percent increase for clinical research. Large, randomized, clinical trials, such as the ones that have proven the efficacy of chemotherapy in colon and breast cancer, are expensive, but they are the most reliable.

We are also seriously concerned about the next generation of investigators who generally feel that the excitement of making a significant contribution in medicine compensates for some of the disadvantages of academic life.

For the National Cancer Institute, we recommend the bypass budget. Specifically, the most important to our group is adequate levels of funding for clinical research.

Regarding cancer prevention and control, we already know, for example, that the mortality from breast cancer could be reduced 30 percent by routine use of screening mammography according to ACS and NCI guidelines, saving approximately 15,000 lives per year.

While many women between 50 and 70 years of age should be receiving yearly mammograms, in actuality, however, 40 percent of these women have never had one mammogram. In other words, these women simply are not getting a test that we know could prevent cancer.

PREPARED STATEMENT

Finally, we would like to support the bypass budget for research grants and centers as well. Without basic research, there can be no clinical trials. We have to take these research advances from the bench to the bedside.

Thank you.

[The statement follows:]

STATEMENT OF KAREN ANTMAN

Mr. Chairman and members of the subcommittee, I am Dr. Karen Antman, an Associate Professor at the Harvard Medical School, testifying today on behalf of the American Society of Clinical Oncology (ASCO).[1] The Society would like to thank you for the privilege of appearing. The public's major concern is that appropriated funds for the National Institutes of Health improve the health of the American people. We believe the funds that have been expended for cancer research have had a major positive impact on the health of the American people and that the current exciting work in research laboratories is already being translated into increased benefits for cancer patients. ASCO members are aware of the constraints of the federal budget and are particularly concerned with the spiraling costs of medical care. In an effort to control the costs of patient care, research has become a vulnerable but we feel inappropriate target for cost cutting. Half way technology is expensive; curative treatment is generally cost effective.

Research Accomplishments

Mr. Chairman, I would like to outline three of the most important ongoing research accomplishments of the last year and how they specifically will effect Americans with cancer.

1. It has been established in large randomized trials (the most reliable kind), that *chemotherapy after surgery can prevent recurrence in a substantial percentage of patients with certain stages of colon cancer*. Colon cancer is the second most common cancer in the United States. Application of this knowledge would have an immediate effect on the treatment of patients with this disease. An estimated additional 2,500 Americans would survive after developing colon cancer. Additional studies have shown that chemotherapy after surgery for relatively early breast cancer could avoid relapse in an additional 4,500 women each year as well. Our major challenge now is ensuring that all of those who could benefit from therapy actually receive it.

2. The second immediately and widely applicable observation is the *activity of proteins called growth factors* in enhancing the recovery and function of the bone marrow and immune function after cancer treatment. These are the major side effects currently limiting cancer treatment. Large trials now confirm that these side effects can be substantially ameliorated with these new agents, decreasing infections and decreasing hospital days. Even very intense treatments such as bone marrow transplant, which is curative in leukemia and lymphoma, can now be performed with substantially decreased side effects and significantly fewer hospital inpatient days. These compounds will enhance the effectiveness of treatment and reduce its cost.

3. One of the most exciting areas unfolding is the finding that common tumors have *characteristic genetic changes*. Previously we did not have specific enough probes to find them. The development of common tumors like lung cancer, breast cancer and colon cancer apparently involves a characteristic sequences of genetic changes. The implications of these discoveries will certainly profoundly affect diagnosis and treatment in the next five years. Persons at high risk of developing specific tumors can be identified. Diagnoses will be more accurate. Recognition of these genetic abnormalities is already aiding in the diagnosis of patients at my own institution. It can be impossible to make a diagnosis with standard techniques in some unusual appearing tumors. These can sometimes now be accurately diagnosed by characteristic cytogenetic changes and appropriately treated.

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[1] The American Society of Clinical Oncology, founded 21 years ago, is comprised of 8000 physicians and scientists specializing in cancer, including prevention treatment, teaching and research. Its members include the nation's leading physicians in medical and pediatric oncology, radiation therapy, surgical and gynecologic oncology, and also basic scientists in pathology, immunology, pharmacology, biostatistics, and other basic biomedical sciences, in literally all of the nation's medical schools, cancer hospitals, centers, and institutes.

All of these advances involve investigational drugs or techniques that are not yet broadly available. ASCO has a major commitment to making promising research drugs and techniques widely available. These examples are only a small example fraction of the remarkable research observations that are being made and will continue to occur if cancer research is appropriately funded. These are also the kinds of findings that make research an exciting field for young physicians.

Funding for FY 1991

We strongly support substantially increased funding for NIH supported biomedical research. Specifically with respect to the NCI, the President's proposed fiscal year 1991 budget provides a 3.9% increase over the 1990 NCI operating budget. This represents a 3.6% increase for cancer research and a 7% increase for AIDS research. When one factors in the deflation factor for biomedical research (5.76%), 2% less research will be done in fiscal year 1991 than in the current year if this budget is approved.

Under the fiscal year 1991 Administration request, the National Cancer Institute will:

Fund 10 less research grants;

Fund 27% of the approved grants, which is in fact 33% less than when the National Cancer Act was signed into law in 1971

Be required to decrease funding for existing grants approximately 20% and 4% for competing and non-competing grants respectively; and

Level fund cancer centers, and cancer prevention and control programs.

I can tell you personally of the impact that these measures have on research grants. Any significant cut in an ongoing, already approved and funded program throws continued research into chaos. Personnel are already hired, and cuts must come out of other expenses or an experienced researcher involved in the program must be let go.

Mr. Chairman, a second, particularly deep concern to the physicians in ASCO is that there will be only a 2.5% increase for clinical research. Large randomized clinical trials such as the ones that have proven the efficacy of chemotherapy in colon and breast cancer, and of the growth factors in decreasing toxicity are expensive; however, they are the most reliable. A 2.5% increase effectively means that fewer trials will be completed this year and fewer answers to important questions will be obtained. We are also seriously concerned about the next generation of investigators who generally feel that the excitement of making a significant contribution in medicine compensates for some of the disadvantages of an academic life as exemplified by low NIH salaries compared to private practice, industry or even to University salaries.

Recommendations: For the National Cancer Institute, we recommend the By-Pass Budget. Specifically, and most important to our group, is the adequate funding levels for clinical research.

For clinical cooperative groups, the addition of $32.6 million above the President's FY 1990 budget level (essentially last year's appropriations level). That additional funding would permit the more rapid completion of important clinical studies already underway as well as an increase in the number of new clinical trials.

It would also provide opportunities to focus on trials in suramin, adoptive immunotherapy and combination cytokine trials, among others; and expand minority participation onto clinical trials as well as persons over the age of 65 into such trials.

Clinical Research Training: There is a serious situation now facing this nation in the area of clinical cancer research training to which I have alluded. The Institute of Medicine in a recent report specifically advocated increased NIH support for clinical investigation, preferably from increased appropriations. The large educational debt incurred by recent graduate physicians, the discrepancy between incomes of clinical investigators and colleagues in private practice, increasing difficulty in funding clinical research from the NIH and other sources, and particularly difficulties in advancement in the academic community were recognized as discouraging the recruitment of clinical investigators. An estimated 1000 new clinical investigators are necessary per year merely to replace existing faculty who retire or who enter private practice. The Institute of Medicine report specifically noted and recommended that the NIH and FDA further examine why larger numbers of large-scale clinical trials are now completed in Europe than in the United States and whether children, women, minorities and the elderly may be inappropriately excluded from participation in clinical trials in the United States. Finally they strongly recommended outcome assessment as an integral part of clinical trials.

We have a generation of young investigators who are excited about their research. They are frequently devastated when the grant they write receives a priority score that five years ago would easily have been funded but this year is not even close. Faced with a substantial debt for their medical education and young families, many abandon promising research. In recognition of the potential loss of a generation of investigators, the National Cancer Institute has appropriately attempted to protect basic research grants. However, protection of funding for bench research has been at the expense of clinical research. We need adequate funding for both.

We, therefore, recommend an additional $7.8 million above the President's 1990 budget base, which would support, through the NCI, approximately 1600 trainees, which would represent a 50% level of payment of approved applications. With these appropriate expansions, many of our concerns about training in our field will be met.

Cancer Prevention and Control: I have already commented on the importance of cancer prevention and control activities currently funded through the National Cancer Institute. We already know, for example, that the mortality from *breast cancer* could be reduced 30% by routine use of screening mammography. This translates into approximately 15,000 lives per year. ASCO unequivocally supports screening mammography according to American Cancer Society and NCI guidelines. While many American women should be having yearly mammography, only 40% of those women in the 40-60 year old group have *ever* had even one mammogram. Thus, the bulk of women who clearly would benefit from screening mammography in the United States simply do not get it.

Members of ASCO who treat adults all have a recurrent frustration, attempting (generally unsuccessfully) to treat *lung cancer* which could have been prevented if the patient had not smoked. I have personally treated 25 and 30 year old smokers dying of lung cancer. ASCO enthusiastically supports any reasonable measure to limit tobacco use. We are completely committed to educate children and adolescents on the risks of tobacco use, and to aid any still healthy adults in their attempts to quit smoking. We have taken the strongest possible public position in support of smoking cessation and deeply appreciate the Congress' activities recently in regard to smoking issues, including smoking on airline flights within the United States.

Successful interventions in cancer prevention and control would have a huge impact on the health of Americans. We therefore urge an increase of 80 million dollars in the National Cancer Institute above the President's 1990 proposed budget to provide for an increased smoking cessation effort, expansion of chemoprevention/nutrition activities, aiding the public and their physicians about the routine screening mammography and especially the augmentation of prevention in clinical trials networks and patient accruals through CCOP.

Research Grants and Centers: Finally, Mr. Chairman, you will be hearing from others about the importance of basic research grants generally, and about cancer centers. We support the By-Pass Budget in funding for both. There will be no new treatments, no new diagnostic tests *without adequate funding* *for basic research.* Cancer centers, which are distributed geographically throughout the United States, currently provide the most efficient means for translating research advances from the laboratory to the clinic. *Coordination of early trials is totally dependent on cancer centers.* There can be no randomized trials of promising treatments if the early pilot studies are not performed by experienced researchers, generally in Cancer Centers.

One Additional Recommendation: In the approximately 20 years since the National Cancer Act was passed, its authorities have been improved in the subsequent legislative authorization renewals. Members of this committee, while not members of the authorizing committee which will deal with the National Cancer Act renewal, are nevertheless members of Congress who will vote on the legislation when it comes before them for full debate. When the National Cancer Act comes up for renewal later this year, we urge that the National Cancer Act be kept intact; that all of the authorities which it now contains not be changed, and that the term of reauthorization be for at least three, and preferably five years.

Summary: Mr. Chairman, we have laid out for you a plan of funding for fiscal year 1991 which we believe will significantly improve the health of Americans. This is a goal that you, throughout your career in the Congress, have so ardently fostered. We strongly urge you to accept the funding levels of the By Pass Budget. Cancer patients need and deserve the most expeditious transfer of research findings into clinical practice.

I would be pleased to answer any questions on these issues.

FACT SHEET

FY 1991 APPROPRIATIONS

NATIONAL CANCER INSTITUTE

CLINICAL RESEARCH

The American Society of Clinical Oncology (ASCO) is concerned about the Administration's proposed FY 1991 budget for the National Cancer Institute (NCI), especially regarding clinical research.

Proposed Increase: The actual proposed increase for the NCI is 3.7%, excepting AIDS research, which does not even meet the biomedical research inflationary rate of 5.7%. Therefore, even without factoring in other matters, 2% **less** cancer research at least will take place in FY 1991 if the Administration's proposal is accepted by the Congress.

The increase for clinical research is even less, 2.5%, or 3% less than inflation.

The NCI: Under the fiscal year 1991 Administration request, the National Cancer Institute will:

- fund 10 less research grants;
- fund 27% of the approved grants, which is in fact 33% less than when the National Cancer Act was signed into law in 1971;
- be required to decrease funding for existing grants approximately 20% and 4% for competing and non-competing grants respectively; and
- level fund cancer centers, and cancer prevention and control programs.

Clinical Research: Under the Administration request:

- fewer trials will be completed this year, and
- fewer answers to important research questions will be obtained.

Large randomized clinical trials such as those which have proved the efficacy of chemotherapy in colon and breast cancer, and of the growth factors in decreasing toxicity, while expensive, are the most valuable.

Clinical Research Advances: These cutbacks in clinical research come at a time of enormous excitement in the field because of research advances this last year:

- It has been established in large randomized trials (the most reliable kind), that **chemotherapy after surgery can prevent recurrence in a substantial percentage of patients with certain stages of colon cancer**. Colon cancer is the second most common cancer in the United States. Application of this knowledge would have an immediate effect on the treatment of patients with this disease. An estimated additional 2,500 Americans would survive after developing colon cancer. Additional studies have shown that chemotherapy after surgery for relatively early breast cancer could avoid relapse in an additional 4,500 women each year as well. Out major challenge now is ensuring that all of those who could benefit from therapy actually receive it.

- The second immediately and widely applicable observation if the **activity of proteins called growth factors** in enhancing the recovery and function of the bone marrow and immune function after cancer treatment. These are the major side effects currently limiting cancer treatment. large trials now confirm that these side effects can be substantially ameliorated with these new agents, decreasing infections and decreasing hospital days. Even very intense treatments such as bone marrow transplant, which is curative in leukemia and lymphoma, can now be performed with substantially decreased side effects and significantly fewer hospital inpatient days. These compounds will enhance the effectiveness of treatment and reduce its cost.

- One of the most exciting areas unfolding is the finding that common tumors have **characteristic genetic changes**. Previously we did not have specific enough probes to find them. The development of common tumors like lung cancer, breast cancer and colon cancer apparently involves a characteristic sequence of genetic changes. The implications of these discoveries will certainly profoundly affect diagnosis and treatment in the next five years. Persons at high risk of developing specific tumors can be identified. Diagnoses will be more accurate. Recognition of these genetic abnormalities is already aiding in the diagnosis of patients at my own institution. It can be impossible to make a diagnosis with standard techniques in some unusual appearing tumors. These can sometimes now be accurately diagnosed by characteristic cytogenetic changes and appropriately treated.

As exciting as these results have proven to be, we must continue the forward research momentum on them; that simply will not be possible with the proposed budget.

Clinical Training: We are concerned that we are about to lose a whole generation of clinical investigators. The large educational debt incurred by recent graduate physicians, the discrepancy between incomes of clinical investigators and colleagues in private practice, increasing difficulty in funding clinical research from the NIH and other sources, and particularly difficulties in advancement in the academic community will be seen as very discouraging by young potential clinical investigators. When the decrease in funding of clinical research itself and the negative impact it will have on new research grants proposals is made known, young researchers will be even more troubled.

Recommendations: For NCI, we recommend the By-Pass Budget levels, which would provide increases above the FY 1990 budget for:

. Clinical Cooperative Groups	$32.6 million
. Cancer Centers	$39.3 million
. Training	$ 7.8 million
. Cancer Prevention and Control	$80.0 million

Overall for the NCI we recommend the By-Pass Budget level of $2.410 million for FY 1991.

Also, our recommendation overall for the National Institutes of Health is $9.2 billion, the number recommended by the Ad Hoc Group for Medical Research Funding, to which we are signatories.

FACT SHEET

REAUTHORIZATION OF NATIONAL CANCER ACT

The American Society of Clinical Oncology requests that the U. S. Senate Labor and Human Resources Committee and the U. S. House of Representatives Subcommittee on health and the Environment continue all major authorities of the National Cancer Act when reauthorizing that Institute's programs during the 1990 legislative year.

Background: On December 23, 1971, the National Cancer Act (P.L. 92-219) was signed into law. Special authorities were provided to the National Cancer Institute (NCI), and a National Cancer Program was established. Among the new features were:

- Appointment of the Director of NCI by the President;
- Permission to develop a By-Pass Budget, which is sent directly to the President and Congress, without the requirement for clearance of Administration officials otherwise required for budget recommendations;
- Presidential appointment of the 3-person President's Cancer Panel, charged with responsibility of reporting to the President any delays or blockages in the rapid execution of the National Cancer Program;
- Presidential appointment of the 18-member National Cancer Advisory Board, which advises on the directions and progress of cancer research, treatment, diagnosis, prevention and control.
- Other authorities were included to establish cancer research centers, develop prevention and cancer control programs, train clinicians and researchers, and conduct research in foreign countries to expedite understanding of cancer from a worldwide perspective, among others.

Recommendation: That all these major authorities be kept intact, that authorized funding levels be set sufficiently high to provide for significant increases in program funding levels, and that the legislative authorities be made for 5 years, but at least for 3 years, to permit stability in the Institute's programs.

Senator ADAMS. This committee last year instituted a program of research. We put $5 million additional into it on breast and cervical cancer education. Do you support this program that we put in last year?

Dr. ANTMAN. Absolutely.

Senator ADAMS. I have held a series of hearings on another matter, on pap smear and so on, so I am somewhat familiar with the work that you have been conducting, and I simply want to state from the Chair that the testing program is absolutely essential. And I cry at times that we do not have full coverage of it because the percentage of prevention is dramatically high.

Dr. ANTMAN. There are two components to this. First of all, we have to recognize that there is something that we can do to save these patients, and second, these patients actually have to get the test or the treatment that is determined to be appropriate. By and large, that has not occurred.

Senator ADAMS. Thank you very much. I appreciate the testimony.

Dr. ANTMAN. Thank you.

STATEMENT OF ALAN D. SCHREIBER, CHAIRMAN, PUBLIC EDUCATION COMMITTEE, AMERICAN SOCIETY OF HEMATOLOGY

Senator ADAMS. Our next witness is Dr. Alan Schreiber, American Society of Hematology.

Dr. SCHREIBER. Thank you, Senator.

I represent the American Society of Hematology, which is the only national organization for the more than 4,000 physicians and biomedical scientists involved in the treatment and study of diseases of the blood.

First I would like to thank you, Senator Adams, and Senator Harkin for your leadership last year in the NIH effort, because the NIH is our major source of research support. And if you would, Senator, I would like you to convey to Senator Specter my personal thanks for his additional efforts to add funding to the NIH budget last year.

Senator, there has been an explosion in molecular biology research. This opportunity gives us an exceptional chance to make incredible advances over the next several years. Already over the past year there has been substantial progress. Molecular biology research has allowed the production of proteins formed in the blood to be administered back to individuals who are deficient in these substances. This has made enormous impact into a whole variety of cancers, for example.

Another molecular biology tool has been used to produce a blood factor that naturally dissolves blood clots, and the administration of this factor has caused the dissolution of blood clots in heart disease and has been used in stroke, as well. It has prolonged survival from heart attacks. It has prevented heart attacks.

It is this kind of progress in molecular biology that offers us a unique opportunity over the next several years to make enormous progress in a whole realm of disorders.

The prospect of actual gene therapy is now a reality and is now at hand. Because of this prospect, we are asking you now to support add-on funds for gene therapy in diseases of the blood.

Now, this explosion in molecular biology technology has important economic consequences. Because of this advance and because of our tradition we have led the world in biomedical research. We have been the fountainhead of biomedical research, and we have the opportunity to lead the world in the biomedical research industry.

However, there is a small window of opportunity if we make the investment now to do it, but we need to do it now. Otherwise, the Japanese and the Europeans will take over the leadership in this industry, as they have done for other technologies and other industries. So we need to invest now, and we are not doing it sufficiently.

For example, the cornerstone of our NIH funding is the investigator-initiated research grant, the competitive renewal, and that has decreased dramatically in the last 3 or 4 years. For example, in the National Heart, Lung, and Blood Institute, which is representative of the NIH as a whole, in 1987, 966 competitive research grants were funded, while in 1990 only 601 are going to be funded.

This represents a decrease of 38 percent, which is a substantial decrease in the number of competitive funded research grants, a truly worrisome development from our point of view. Similarly, from our point of view, this makes no sense.

PREPARED STATEMENT

This investment in biomedical research has enormous economic and scientific consequences. And it is because of this opportunity that we ask you now to support the Heart, Lung, and Blood Institute at the $1.48 billion level, and the NIH at the $9.2 billion level.

Thank you, Senator.

[The statement follows:]

STATEMENT OF ALAN D. SCHREIBER

Mr. Chairman and Subcommittee Members:

On behalf of the American Society of Hematology and its more than 4,000 members, I wish to thank you for the opportunity to present testimony before the Subcommittee again this year in connection with the legislation for the fiscal 1991 appropriations for the National Institutes of Health.

I am here today representing the American Society of Hematology. The Society is the only national organization of hematologists and is composed of physicians and biomedical scientists who are concerned with research, patient care and teaching as they relate to blood and diseases which affect the blood.

Before presenting our views about this legislation, I would like to express my gratitude to the members of this Committee and to the entire Congress for their strong support on behalf of biomedical research and hematology. We appreciate your long-standing commitment to the programs of the National Institutes of Health. Most importantly, we thank you for the strong support you have given to investigator-initiated research. The creative imagination of our nation's scientists represents one of our country's greatest assets. The support that you direct to these scientists has brought considerable benefit to each and every one of us and promises enormous important benefits in the years ahead.

The blood is a complex human tissue. Blood consists of both cellular and fluid components, both of which are critical to maintaining many of life's processes. Blood flows through every organ of the body and abnormalities of the blood can affect many organ systems. Therefore, research concerning the blood is supported by a number of Institutes, particularly the National Heart, Lung and Blood Institute, the National Cancer Institute, and the National Institute of Diabetes, Digestive and Kidney Diseases. This spectrum of support has been most productive for hematology research and for the broad research mandates of the individual institutes.

Over the past year there has been an explosion in molecular biology research. This new research has opened up new approaches for the treatment of a wide range of blood disorders. For example, molecular biology techniques have enabled the identification, isolation and production of a wide range of factors that control the growth and production of normal human cells. One such growth factor is granulocyte/macrophage colony stimulating factor or GM-CSF. GM-CSF is a normal growth factor that regulates the production of the white blood cells. The white blood cells or granulocytes/macrophages are a critical component of our defense against infection and are produced in the bone marrow. Their deficiency leads to death in a wide range of disorders which affect the blood. Hematologists and other biomedical scientists using molecular biology techniques have cloned the human gene for GM-CSF. They were then able to characterize the precise biochemical structure and function of GM-CSF. Finally and importantly, they were then able to interact with private industry to produce GM-CSF, again using molecular biology techniques, in large amounts for patient use.

During the past year GM-CSF has been successfully used in blood disorders characterized by the inability of the bone marrow to produce white blood cells in adequate numbers. One such disorder is aplastic anemia, a disease in which the bone marrow is deficient in its production of red blood cells, leading to anemia; blood platelets, leading to bleeding; and white blood cells, leading to infection. GM-CSF therapy has raised the white blood cell count sufficiently (often to normal levels) in patients with aplastic anemia so as to prevent the onset of infection. GM-CSF therapy has already saved the lives of numerous patients with this dreaded disorder.

GM-CSF treatment also is now being used in cancer therapy. Chemotherapy for the treatment of many cancers has the disadvantage of inhibiting the bone marrow's ability to produce adequate numbers of white blood cells. This has limited the successful use of a wide variety of chemotherapeutic agents in the therapy of cancer. GM-CSF promises to be an important adjunct in cancer therapy. By helping to overcome the toxic effects which chemotherapy has on bone marrow white blood cell production, GM-CSF may permit the use of a wider range and larger dosage of chemotherapeutic agents. GM-CSF has already been shown to accelerate the recovery of the bone marrow and white blood cell count following their depression after chemotherapy. Furthermore, GM-CSF can be administered by the patient himself at home, maintaining the white blood cell count and avoiding costly hospitalizations.

The fluid and cellular constituents of the blood interact with the blood vessel wall causing coagulation of blood and thrombosis. This process, when not functioning properly, can lead to such vascular disorders as stroke in cerebrovascular disease and heart attacks in coronary-artery disease. Stroke and heart disease are two of the major causes of death in Americans. Our understanding of the molecular events involved in blood-blood vessel wall interactions are helping to lead to therapies which help prevent the progression of arteriosclerosis and thrombosis and which will help control these devastating vascular occlusive diseases. One recent advance is the availability of a naturally occurring reagent, tissue plasminogen activator, that is able to lyse and dissolve blood clots. The gene for tissue plasminogen activator produced by blood-vessel wall cells has now been cloned. This has led to the production of plasminogen activator for therapeutic use, using molecular biology techniques. Tissue plasminogen activator has now been licensed and is being used generally with success. Over the past year many patients with blood clots have been treated successfully with this new thrombolytic therapy. For example, tissue plasminogen activator has been shown to be effective for dissolving blood clots in blocked coronary arteries in the early stages of a heart attack (myocardial infarction). This work has resulted from coupling advances in our understanding of the function of blood vessel wall cells with our increased knowledge of molecular biology which permits study at the level of the gene.

Our advances in molecular biology also have paid major dividends in our ability to control anemia. Erythropoietin is a growth factor produced by the kidneys which stimulates the production of red blood cells in the bone marrow where they are normally produced. About 85,000 Americans suffer from kidney failure and the accompanying decrease in red blood cells or anemia. Hematologists, using new concepts in molecular biology, developed a method to manufacture this human hormone and to administer it to anemic patients with kidney disease.

Recently, this development has had a significant impact on the treatment of anemia associated with end stage kidney disease and other disorders associated with bone marrow failure to produce adequate red blood cells. Its use is helping to conserve the national blood supply by reducing the need for red blood cell transfusion in these patients. Erythropoietin therapy also holds promise for the many patients with sickle cell disease in whom it stimulates the production of normal red blood cells and, thus, favorably influences the clinical course. Erythropoietin will likely also raise the blood count in patients with Cooley's anemia. Erythropoietin therapy not only improves the quality of life of such patients with anemia, but also provides important economic benefits, for example, by avoiding hospitalization and the frequent use of blood transfusions.

GM-CSF and erythropoietin are only two of several newly characterized growth hormones which are becoming available for patient use. Scientists, using new molecular biology approaches, have been able to clone the genes for several growth factors, as well as naturally occuring coagulation proteins such as those deficient in hemophilia, which has resulted in their development for clinical use. A whole new class of therapeutic agents will likely be developed for a wide range of human diseases.

Our advances in molecular biology are having an impact in the treatment of two hereditary blood disorders that afflict a substantial number of Americans, sickle cell anemia and Cooley's anemia. Using a molecular biology approach to develop transgenic animals, scientists have developed mice which make human hemoglobin. Scientists are now able to implant sickle hemoglobin genes in these animals and cause production of the human sickle cell hemoglobin. Such animal models produced by molecular biology approaches facilitate the necessary studies to explore experimental treatment for these disorders.

The treatment of these diseases as well as a large number of other disorders which affect the bone marrow and immune system has been influenced by the development of bone marrow transplantation as an increasingly effective therapy. One new approach is to combine the technology of bone marrow transplantation with molecular biology. This can be done by performing gene replacement in the bone marrow stem cells of the patient, and to utilize these corrected stem cells for bone marrow transplantation (autotransplantation). This approach bypasses the immunologic problems associated with traditional bone marrow transplantation. However, it is difficult, at this time, to insert such genes into bone marrow stem cells that will induce sufficient output of gene product in the developed blood cells to which they give rise. There has, however, been great progress in this direction. For example, proteins can be expressed in mouse bone marrow cells after the gene is inserted into mouse bone marrow stem cells. Therefore, we believe additional funds should be provided for gene replacement therapy and autotransplantation.

The interaction between biomedical scientists and private industry has led to the growth and development of a potentially important aspect of our economy, the biomedical industry. For many years the United States has been the fountainhead of biomedical research. This provides us with the opportunity to take the leadership in the biomedical and biotechnology industry, with important economic consequences. However, in order to assume this economic leadership and maintain our leadership in biomedical research, the following needs to be accomplished. First, we must obtain the necessary funding to restore our biomedical research training programs to their previous levels. Second, we must reverse the alarming downward slide in the number of NIH competitive research grants awarded. The cornerstone of our biomedical research programs is NIH investigator-initiated, non directed research. As you know, each NIH institute awards each year a number of research grants on a competitive basis. It is these competitive NIH research grants, our major source of research funding, which are decreasing dramatically in number. For example, for NHLBI in FY 1987, 966 competing research grants were awarded; in FY 1988, 851 were awarded; in FY 1989, 698 were awarded; in FY 1990 it is estimated that only 601 competing research grants will be awarded. This represents a 38% decrease from FY 1987, a development of major concern. A similar magnitude in reduction in number of competitive research grants awarded has occurred in NCI and NIDDK. This is in large part due to the increased cost of biomedical research and is of major concern to biomedical scientists. In effect, these reductions in number of competitive competing grants are reducing the number of active biomedical scientists. Further, these reductions are discouraging our young, talented students from entering a career in biomedical research. It is with this in mind that we recommend working together to restore the number of research grants towards the FY 1987 levels. This not only represents a wise investment in the health of our country, at this critical juncture when there is a virtual explosion in molecular biology research opportunities, but it also represents a wise investment in our future economic health.

It is in this spirit, that the American Society of Hematology makes the following recommendations: That appropriations for FY 1991 for the National Heart, Lung and Blood Institute, the National Cancer Institute and the National Institute of Diabetes and Digestive and Kidney Diseases be funded at no less than the levels indicated below.

NHLBI:	$1.48 billion
NCI:	$2.4 billion
NIDDK:	$697 million
NIH:	(overall $9.2 billion).

Our ultimate goal is for 40% of overall NIH approved investigator-initiated research grants to be funded.

We also strongly recommend that the committee provide increased funding for gene therapy and autotransplantation (researchers from the NHLBI made medical history last spring by inserting new genetic material into human cells, returning the cells back to the patient, and then tracking the gene-engineered cells in the patient's circulatory system two months later); for the recently proposed NHLBI intramural clinical bone marrow transplant program; ;and for the Specialized Centers of Research in the NHLBI Extramural program. (The NHLBI and NIDDK are providing remarkable leadership in the hematology field.)

Finally, we believe the research opportunities for gene replacement therapy are so considerable that the NIH be requested to develop in coordination with hematologists a comprehensive analysis of these research opportunities. We would also recommend that this include an analysis of the manpower and funding requirements necessary to take advantage of these opportunities.

Senator **Adams**. Thank you very much, Doctor.

I want to mention a particular thing that we are just going to have to deal with. You, again, are at a critical juncture because nearly everyone knows that this committee has doubled the funding at NIH since 1982, while the other domestic programs in the discretionary area where the funds are available to this committee has been almost flat. That is because we have believed that we should be moving in the research area, and I support the increase in funding elsewhere, and I hope that we will have funding available.

But in your particular case, I, again, have some personal experience with this with the private research and the private development that is going ahead, and I would just like your comment on what do you see as the role of private industry in a partnership with the Federal Government and the scientific research community in advancing biomedical research in the United States?

I know there are a number of people out there. We have a whole range of problems, from registering new drugs to the material that is coming from the labs, but talk to me a little bit about the partnership or what you envision is the best way to approach this.

Dr. **Schreiber**. All right. I will do that. I just want to say first, though, in relation to your first comment, again I thank you for the increase in the NIH funding. But primarily because of the increased cost of doing biomedical research, which has increased dramatically over the last few years, those competitively initiated research grants have declined. It is an investment that we need to make.

Now, I think the partnership with industry, which is something the Japanese do very well, is something that we really need to address. But the basic science, the investigator-initiated research, is going to really have to come out of the NIH funding because the technology or the industry, industrial funding by itself is targeted funding for specific projects.

But if we can put as an investment a considerable increase in funding in basic research through the NIH, then it will be channeled into the partnership and foster at the Federal level that partnership with industry. That can be channeled into the partnership with industry, where we will pay back economically enormously what the investment is at the Federal level. We will lead the world, beyond a doubt, in the biomedical research industry, which is going to be a burgeoning industry.

So it is an opportunity. And since we have been going down and people have been discouraged about going into research and getting scientists into research for all the reasons that you have already heard, we only have a window of opportunity.

So we need to invest now plus foster that relationship with the biotechnology industry. We just have to get that message across somehow because it is really a dollar enormously well spent for our country, both scientifically and economically.

Senator **Adams**. Thank you very much, Doctor. I appreciate your testimony. That particular issue covers a broad range of things that are occurring in the United States, but this happens to be a particular one. We are having a great problem in all of our basic research in translating it into the actual technology in the field, which the Japanese are doing very well using our basic research.

So I know we are in the position that you state with regard to our basic research being very good. I ask you the question because I am very concerned that we somehow translate this over into our system, because if we do not, it is obvious that it will go elsewhere, either to Europe or to Japan.

I address that really to all of those that are in the audience here this morning, that we are aware of that being a significant problem, and those that wish to submit information on it, the committee would be pleased to receive it. It is something we must solve or else we will lose this opportunity, and that would be tragic.

Dr. SCHREIBER. Right. The investment is an important component of that solution.

Senator ADAMS. Thank you very much, Doctor.

Dr. SCHREIBER. Thank you.

STATEMENT OF ALICE FORDYCE, THE COORDINATING COUNCIL FOR CANCER RESEARCH

Senator ADAMS. Our next witness is Ms. Alice Fordyce, Coordinating Council for Cancer Research. Welcome, Ms. Fordyce. I hope that Mary is well, and I am glad to see you here this morning.

Ms. FORDYCE. Thank you, Mr. Chairman.

I would like my longer statement to go into the record, and I will now summarize my comments.

Senator ADAMS. Without objection, your entire statement will appear in the record as though given.

Ms. FORDYCE. Thank you.

I am Alice Fordyce, executive vice president of the Albert and Mary Lasker Foundation. I am also vice president of the U.S. Coordinating Council for Cancer Research, and today I am honored to appear before you on behalf of this council.

The CCCR is a voluntary, nonprofit organization which implements the support of worldwide cancer research coordination. This coordination is achieved through symposia, workshops and joint research projects, and complements the existing public and private efforts of every nation involved in cancer research.

We live in hope for the day when cancer is eradicated from the world. Turning this hope into a reality is possible only if we marshal the talents of all of the world's outstanding scientists in all fields of cancer research.

International collaboration has accelerated discoveries in many technological fields. Now it is time to apply this same formula to a global war against cancer. Cancer has no boundaries. Every year, over 7 million people worldwide and 500,000 here in the United States die of cancer. International coordination would provide a sound basis for utilizing our research findings and bringing the best minds to the worldwide eradication of cancer and saving these lives.

This year, the National Cancer Advisory Board has sent to the President the fiscal year 1991 bypass budget, a needs budget for the NCI, of $2.4 billion. The CCCR supports this level of funding and urges you and your colleagues to approve this request.

The President's budget would fall short of this funding level by $716 million. Without this $716 million, fewer research grants will be funded in fiscal year 1991, and only 27 percent of approved grants will be funded at all. Downward negotiations of 20 percent for competing grants and 4 percent for noncompeting grants will be necessary.

In this funding climate, it is virtually impossible for the NCI to commit dollars to crucial international research efforts, but we live in an age of international competition. In order to really maintain our crucial international leadership, the Congress will have to support the NCI's major research programs. Already Japan, West Germany, and France commit a greater percentage of their GNP to biomedical research than we do in the United States.

The cold war is over. Now we must move away from huge defense budget programs and move toward the goal of a healthier Nation and world.

PREPARED STATEMENT

If this committee will approve funding of the $2.4 billion budget for these cancer programs, many scientific and technological breakthroughs which will have international consequence could be achieved, and millions of lives could be saved. We will be permanently indebted to you and to the members of this committee for this budget approval.

Thank you.

[The statement follows:]

STATEMENT OF ALICE FORDYCE

Mr. Chairman, I am Alice Fordyce. It is my honor to appear before you today on behalf of the Coordinating Council for Cancer Research (CCCR) of whose board of Directors I am a Member.

The CCCR is a non-profit organization which focuses support on worldwide coordination in cancer research by promoting and facilitating collaboration and cooperation between teams of international cancer research scientists. Such collaboration is achieved through symposia, workshops and joint research projects. This type of activity complements the existing public and private efforts of every nation involved in cancer research.

We look forward to the day when cancer is eradicated. Turning this hope into a reality is possible only if we marshall the talents of the world's outstanding scientists in all fields of cancer research. International collaboration has accelerated discoveries in many technological fields. The time has come to apply this same formula in a global war against cancer. International cooperation and international competition both must be promoted if we ant to accelerate the pace of progress and have a cost-effective approach to biomedical research.

Cancer has no boundaries. Every year over 7 million people world-wide die of cancer, almost equivalent to the population of New York City. International collaboration through two basic programs of education and training would provide a sound basis from which to begin to harness and utilize our research findings and bring the best and brightest minds to the task of solving the cancer puzzle.

This year the National Cancer Advisory Board has transmitted to the President the FY 1991 By-Pass-Budget, a needs budget, for the NCI of $2.4 billion. The CCCR supports this level of funding and urges you and your colleagues to take this request under consideration. The President's Budget would fall short of this funding level, by $716 million. Without these resources, many research opportunities will go unfunded and existing research efforts will not be stabilized. The impact of the FY 1991 President's Budget is highlighted below:

* 10 fewer grants will be funded in FY 1991 than were funded in FY 1990.

* Only 27% of the approved grants will be funded.

* Downward negotiations of 20% for competing grants and 4% for noncompeting grants will be necessary.

* Level funding of cancer centers, and cancer prevention and control programs will prevent these programs from stabilizing or addressing new initiatives.

With this type of funding climate, it is virtually impossible for the NCI to commit dollars to crucial international research efforts.

We live in an age of international competitiveness. The U.S. has long been a leader in the area of biomedical research and the National Cancer Institute is revered around the world as a premier institution which serves to support cancer researchers of the highest caliber. In order to remain at the top, however, the Congress will have to continue to support the NCI's research programs in the same generous fashion as in the past. Already Japan, West Germany, and France commit a greater percentage of their GNP to biomedical research than we do in the United States. The pioneering achievements in biomedical research are symbolic of the scientific leadership of the United States which no other nation can equal.

The cold war is over. We are entering into a time where we have the luxury to move away from huge defense programs and can move towards a goal of a healthier nation and world.

Reaching the level of commitment which is recommended in the By-Pass-Budget is a challenge. However, we must realize these research opportunities - for this and future generations. The By-Pass-Budget would allow for the following:

- Full funding of a 50% award rate.
- Full funding of noncompeting research grants.
- Full funding of existing cancer centers as well as restoring the 10 centers phased out in the past two years and adding 5 new cancer centers.
- Expand the number of clinical trials.
- Expand cancer prevention and control programs.
- Address the needs of special populations such as minorities and over-65 populations.
- Expand the cancer information dissemination activities.
- Expand on vaccine development efforts.

In this country alone, over 500,000 Americans die every year of cancer. This is the equivalent to one Congressional District. If we commit adequate funding for the existing cancer program, it is estimated that 178,000 of those individuals would live. We are on the verge of many scientific/technological breakthroughs which will have international consequence.

I would like to leave you with this thought, in a time of peace, the U.S. spends more on Defense R&D in 24 months than has been committed to the NIH research budget in its entire 100 year history. Please help us to change our funding priorities. It has been my pleasure to appear before you.

Senator **Adams**. Thank you, Ms. Fordyce.

You mentioned that Japan and West Germany commit a greater percentage of their GNP for biomedical research than we do here. You can submit this for the record if you want, because I do not expect you——

Ms. **Fordyce**. Please do.

Senator **Adams**. How much does Japan commit and how much do we commit as a percentage of our GNP to biomedical research?

Ms. **Fordyce**. I am not sure of the latest figures.

Senator **Adams**. Do you want to submit that to the record for us?

Ms. **Fordyce**. We will have them for the committee, for the report.

Senator **Adams**. Fine. Thank you very much. We appreciate your testimony.

Ms. **Fordyce**. Thank you very much.

STATEMENT OF HERBERT PARDES, PRESIDENT, AMERICAN PSYCHIATRIC ASSOCIATION

Senator **Adams**. Our next witness is Dr. Herbert Pardes, president of the American Psychiatric Association.

Doctor, we welcome you.

Dr. **Pardes**. Good morning, Senator. Thank you.

I am also dean of the College of Medicine at Columbia University, and I was director of the national institute from 1978 to 1984—the National Institute of Mental Health.

What I think has happened in this field is simply startling in the last 10 to 15 years because we are genuinely in a major revolution. Perhaps that is particularly noteworthy if one can take a look at a couple of journals that have just come out, one from Newsweek highlighting the remarkable drug, Prozac, for uses in depression and a variety of other psychiatric disorders, and another in the U.S. News and World Report talking about beating depression.

Things have really changed dramatically. What has happened is people have had increased hope by virtue of some of these improvements, and also some decrease in stigma of mental illness, but what is critically needed is a sustaining and a building of the resources. This is not just spending; this is an investment.

New findings are constantly coming forward from genetics, immunology, imaging, neurobiology on the issues of mental illness. We developed tricyclics for depressions; neuroleptics for psychosis; clozapine, a new drug for schizophrenia; chlomipramine for obsessive-compulsive disorder; new behavioral and psychotherapeutic techniques; new techniques of working with multiple families for people who have schizophrenia—and one could go on and on with the various therapeutic advances.

But the figures remain grim: 20 percent of the U.S. population has mental disorders; mental disorders account for the majority of patients in hospitals; 12 percent of children have diagnosable mental illnesses; 7.3 percent of adults have anxiety disorders, 5 percent depression, 1 percent schizophrenia, 1 percent obsessive-compulsive disease, 4 million Alzheimer's, 10.5 million alcohol, 12 percent use cocaine, and, in fact, cocaine is the leading cause of emergency room visits; and one-third of the homeless have mental illness.

The Nation certainly has many challenges, and we are aware of the fact that the budget is tight, but an investment in research can bring enormous dividends.

Now, many leaders have recognized that, as have many other agencies. Congressman Conte is advocating the decade of the brain; Senator Domenici, the national plan for schizophrenia. The Institute of Medicine calls for a major initiative in children's mental health.

The President's budget, however, would have an absolute freezing effect on research. It is a dangerous policy, and your question before about the investment in R&D over the GNP is well taken. In fact, we are crossing. In the early 1960's, the United States had about 2.8 percent of its budget, of its GNP, invested in civilian R&D. We are down now to about 1.7 percent. That is just the reverse in four other countries: Japan, West Germany, France, and one other.

Do we want to hand over the biomedical research lead to other countries? The President's budget would, in essence, reduce the current level of research support, do nothing to address the deteriorating capital and infrastructure for research, does nothing for the declining number of young researchers, does nothing for the enormous number of researchers being turned down and leaving this field.

We must increase the research. We must increase the research training. We have recommended research budgets for NIMH of $675 million, for NIDA of $332 million, for NIAAA, the Alcohol Institute, of $189 million. These include research, the support and training of young researchers, which is critical—that budget has just deteriorated remarkably—and the addressing of the AIDS question.

Research reduces costs to society. The introduction of lithium some 15 years ago has led now to $39 billion in savings in reduced costs and increased productivity. We can do it with other therapies.

If we get the kind of increased research support we are talking about, we can use the promise of genetics, of imaging, of brain research to sort out diseases, determine causes and develop better treatments for Alzheimer's, schizophrenia, and manic-depressive disease.

We can determine what causes alcoholism and figure out what are the predisposing factors. We can develop new treatments for drug abuse. We can expand research on the identification of cofactors that affect the vulnerability to AIDS and also the kinds of behaviors that lead to AIDS. We can launch an attack on children's diseases.

We can use tools to clarify how memory works. To give you a sense of the excitement of the research, researchers are talking about what particle in the brain carries new information. How does one record a new fact? If you have seen my face or know me for the first time, what is the filing system in your brain that allows you to remember? How can we fortify that so we do not send millions more people as the population ages to institutional and nursing home care?

And we can get better treatment for an increasing problem, the comorbidity of psychiatric illness and alcoholism and drug abuse in the same patient.

PREPARED STATEMENT

I might make one other comment, and that is that among the obstacles to be addressed is the need to protect animal research because that is critical. Many of the activists have produced distorted, propagandizing material to make animal research look like a bad egg. It is critical for research, as are these other resources.

I will stop there. Thank you, Senator.

[The statement follows:]

STATEMENT OF HERBERT PARDES

Mr. Chairman and members of the Subcommittee, I am Dr. Herbert Pardes, President of the American Psychiatric Association, a medical specialty society representing more than 36,000 psychiatrists nationwide. I am also Dean of the College of Physicians and Surgeons of Columbia University and a former Director of the National Institute of Mental Health. I testify again this year on behalf of not only the APA, but the American Association of Chairmen of Departments of Psychiatry, the American Association of Directors of Psychiatry Residency Training and the American Society of Adolescent Psychiatry. I also wish to associate the APA with the testimony of the Ad Hoc Group for Medical Research Funding and the Coalition for Health Funding.

Since my first appearance before this Subcommittee over a decade ago, the nation has witnessed a dramatic revolution in the science of understanding and treating mental disorders and the interrelated illnesses of alcoholism and drug abuse. We have seen the introductions of tricyclics and MAO inhibitors for the treatment of depression; of neuroleptics for those suffering from psychoses; of clozapine for those unresponsive to other neuroleptics; and chlomipramine for obsessive-compulsive disorders. We have also seen the increasing use of dynamically oriented but time-limited psychotherapy, as well as new techniques of crisis intervention, multiple-family group treatment for families with schizophrenic relatives, new behavioral treatments, and documented proof of the effectiveness of psychotherapy in the treatment of depression. Our field can now offer a variety of treatments.

Simultaneously, public understanding of the complex nature of the mental and addictive disorders; their underlying co-morbidities and interrelationships; and the challenges of tailoring appropriate treatment to the affected individual has evolved and heightened, slowly serving to eradicate the dangerous social stigma attached to these disorders which prevent individuals from seeking necessary and appropriate treatment. Research continues to be the most potent tool we have for generating valid bases for hope that mental and addictive disorders are amenable to treatment and for destigmatizing these disorders. The urgent need for this research investment is seen in the grim data, Mr. Chairman. For example, the aggregated rate of psychiatric disorders for children, adults and elderly exceeds 20 percent, or more than 40 million, of the U.S. population annually. Mental disorders account for the majority of patients receiving clinical hospital care in the United States, yet research shows that only one-fifth of those identified as having a mental illness are currently under treatment. It may be surprising to learn that of the one-quarter of the U.S. population under age 18, at least 12 percent, or 7.5 million, of these children have a diagnosable mental illness; approximately 7.3% of U.S. adults have suffered from an anxiety disorder; affective disorders, which include major depression, manic episodes, and dysthymia (a milder form of depression), affect approximately 5 percent of the adult population; schizophrenic disorders, which can be the most disabling of mental illnesses, occur in approximately 1 percent of the U.S. population, and approximately 40 percent of all hospitalized psychiatric patients in the United States suffer from schizophrenic disorders; an estimated 4 million elderly Americans suffer from Alzheimer's disease; an estimated 10.5 million United States adults exhibit some symptoms of alcoholism or alcohol dependence, and an additional 7.2 million abuse alcohol but do not yet show symptoms of dependence; nearly one-third of all new cases of AIDS are occurring in intravenous drug users; 12 percent of Americans have used cocaine, which is the leading cause of drug-related emergency room visits; nearly a third of the population of homeless single adults in the Nation suffer from severe and disabling mental illness. As you can see, the ADAMHA mission to provide national leadership to America's mental health and substance abuse treatment and prevention efforts is awesome.

Despite the enormous challenges facing the nation, the scientific, practitioner and citizen communities are confident that with an adequate and sustained investment the research supported by the three ADAMHA institutes will yield economic and human dividends far in excess of the modest "down payment". The answer to the Congressional concern about clinical services and service systems also lies in the information obtained through ADAMHA's basic biomedical and behavioral research programs. Congressman Conte's "Decade of the Brain" plan for the neurosciences and the Senator Domenici inspired National Plan for Research on Schizophrenia are two important linkages to the future of mental health care delivery. So is the recent report from the Institute of Medicine on specific program and policy recommendations for a national initiative to expand research on child and adolescent mental disorders and the ongoing NIMH research in the area of mental disorders in the elderly.

Mr. Chairman, you know better than I that the national budget situation is in dire straights, but I feel you would agree that the nation cannot forego a stable research investment and continue instead to pay the ever-increasing direct costs of mental illnesses and addictive disorders. I know that the Congressional Budget Committees are not likely to allocate substantial new funds for the support of domestic discretionary programs. These severe funding limitations will only jeopardize the realization of immediate scientific opportunities now on the verge of fruition. The President's FY 1991 proposed ADAMHA research budget will significantly reduce the current level of research effort and have a severe chilling effect upon researchers in the field, thereby slowing the quest for knowledge necessary in conquering the devastating human tragedies of mental illnesses and substance abuse. Presently, the scientific pool of senior researchers is not being sufficiently replenished with young researchers. Although there is a growing interest among young physicians in entering the field, the numbers remain alarmingly low. Unfortunately, the commitment of funds for ADAMHA research training has fallen far short. Our budget proposal would effectively double the research training programs of the three institutes.

In contrast to the President's budget, the APA and the Mental Health Liaison Group Coalition propose that the research budgets for the three ADAMHA institutes be increased to respectable levels, as follows: $675 million for the NIMH; $332 million for the NIDA; and $189 million for the NIAAA. These recommendations include critical research training and research management and support activities, as well as support for AIDS research. These recommended budgets would allow the institutes to support high quality research project grant applications at rates which will not dissuade excellent investigators from even applying for assistance. For the NIAAA this would mean supporting 225 new and competing grants as opposed to the 81 able to the supported under the President's budget; 328 new grants for the NIDA versus the President's 245; and 625 for the NIMH as opposed to 278 under the President's request. These are startling increases at first glance but only modestly in excess of the number of new projects initiated in the present fiscal year.

History has repeatedly demonstrated the cost-beneficial nature of this investment. For example, the introduction of lithium for the treatment of manic-depressive illness led to a $39 billion cost savings in reduced medical costs and increased productivity in the fifteen years since its discovery. This is 10 times the total invested in research by NIMH since lithium's effects were discovered. We in the field have the capability to reap comparable benefits for patients with many other mental and addictive disorders by fully exploiting the strong scientific base which exists. We are confident that with increased support the field will be able to: clarify the underlying mechanisms of the major anxiety and depressive disorders through new imaging studies and develop more effective treatments for these disorders; evaluate the impact of clozapine on subgroups of schizophrenic patients who have not responded well to standard medications; undertake additional linkage studies to identify genes that underlie such severe mental disorders as schizophrenia, manic-depressive disorder, and Alzheimer's disease; discover that a series of biochemical, physiological and behavioral characteristics of an individual may be markers of individual predisposition to alcoholism; make more rapid progress in the development of new medications for the treatment of drug abuse; expand research on the identification of cofactors that affect HIV vulnerability, transmissibility and disease course; expand research on the effects of maternal drug use on infant development; initiate a multisite longitudinal trial on child and adolescent mental disorders, with special emphasis on the continuity of child and adult mental disorders; and refine new diagnostic techniques for Alzheimer's disease.

Mr. Chairman, these are only samples of the formidable challenges that lie ahead. But there are equally remarkable opportunities to make quantum leaps in progress. The alternative budget proposal developed for your consideration has been thoroughly reviewed and assessed with full awareness of the fiscal crisis that confronts the nation. It has been endorsed by the Ad Hoc Group for Medical Research Funding. We agree with the Ad Hoc Group and the Coalition for Health Funding, that the promise of research for reducing human and economic costs, as well as for contributing positive benefits to the nation's international competitive position, makes support for biomedical and behavioral research a high priority investment in the nation's future.

The ADAMHA mission is broad and, as such, contains many diverse, yet interwoven, programs. Briefly, we propose for your consideration a $26 million appropriation for NIMH Clinical Training and $3 million for NIDA/NIAAA clinical training to better ensure the placement of personnel in shortage areas and in public facilities and to improve the quality of training—in a field of exploding new knowledge from research advances—provided to mental health and sustance abuse specialists.

The Alcohol, Drug Abuse and Mental Health Block Grant which now also includes the Alcohol and Drug Treatment and Rehabilitation Block Grant requires approximately a doubling of the President's budget request to $3 billion. There can be no overriding reason for holding at the current appropriation this program which provides funds to the states to support alcohol, drug abuse and mental health prevention, treatment and rehabilitation services to those in dire need. We recommend adequate increases to support the vital activities of the Office of Substance Abuse Prevention and the new Office of Treatment Improvement.

We request Congress to reauthorize and then appropriate $10 million for Comprehensive Planning Grants for Seriously Mentally Ill Persons to assist states in developing community care systems for the chronically mentally ill.

We ask Congress to fully fund the NIMH and NIDA/NIAAA homeless demonstration projects and we seek your support for a $100 million appropriation to expand the state homeless grant program.

We propose increases above the President's budget to permit ADAMHA to continue with important initiatives in AIDS research and to demonstrate the efficacy of delivering mental health treatment services for persons with HIV infection as authorized in last year's omnibus AIDS legislation.

Mr. Chairman, while acknowledging the need to address budget deficits in accordance with the Gramm-Rudman-Hollings Balanced Budget Act, we do not believe human services programs, including those of ADAMHA, should bear this burden. These programs have already been pared to the bone, and Congress should look at alternate means to control the federal deficit.

Thank you again for this opportunity to appear before your Subcommittee.

ADAMHA
(in $millions)

	Approp. FY 90	Pres. FY 91	Curr. Services FY 91	Our Proposal FY 91
NIMH				
Research	$389.6	$413.5	$465.2	$579.3
Research Training	$ 24.2	$ 25.8	$ 25.3	$ 47.6
Research Mgt./Support	$ 40.1	$ 42.6	$ 42.6	$ 48.5
	$453.9	$481.9	$533.1	$675.4
Demonstrations				
Community Support	$ 24.3	$ 22.8		
Prevention	$ 4.0	$ 4.0		
Homeless	$ 6.0	$ 6.0		
	$ 34.3	$ 32.8	$ 35.8	$ 45.8
Protection/Advocacy	$ 14.0	$ 8.0	$ 8.0	$ 22.0
Clinical Training	$ 13.5	$ 5.0	$ 14.1	$ 29.0
State Planning Grants	$ 0	$ 0	$ 0	$ 10.0
NIDA				
Research	$220.6	$258.9	$254	$291.9
Research Training	$ 3.9	$ 4.9	$ 4.1	$ 7.0
Research Mgt./Support	$ 27.1	$ 33.3	$ 30.4	$ 33.3
	$251.6	$297.1	$288.5	$332.2
Treatment Demonstrations	$128.1	$109.9	$133.5	$133.5
NIAAA				
Research	$131.6	$137.6	$159.2	$170.2
Research Training	$ 3.2	$ 3.4	$ 3.3	$ 6.2
Research Mgt./Support	$ 11.1	$ 12.2	$ 12.2	$ 13.3
	$145.9	$153.2	$174.7	$189.7
Homeless Demonstrations	$ 16.4	$ 9.5	$ 17.1	$ 17.1
Office of Sb.Ab.Prevention	$193.4	$261.9	$203.7	$263.0
Office of Trmt. Improvement				
Treatment Programs	$133.6	$117.7	$139.3	$145.6
Trmt. Mgt./Support	$ 2.1	$ 4.1	$ 4.1	$ 5.0
ADM Block Grant	$1192.9	$1292.8	$1242.9	$3000.0
Homeless Grants	$ 27.8	$ 33.7	$ 33.7	$ 33.7
Buildings/Facilities	$ 0.2	$ 3.1	$ 3.1	$ 3.1
Office of the Admin.	$ 10.3	$ 12.4	$ 11.2	$ 14.2
ADAMHA AIDS Budget (DO NOT ADD)				
NIMH Research	$ 68.4	$ 78.1	$ 87.2	$ 99.9
NIDA Research	$ 56.5	$ 76.5	$ 71.7	$ 80.3
NIDA Demonstrations	$ 81.6	$ 63.3	$ 84.9	$ 84.9
NIAAA Research	$ 8.2	$ 9.2	$ 11.2	$ 12.2
Buildings/Facilities	$ 0	$ 1.6	$ 1.6	$ 1.6
Off. of Administrator	$ 0	$ 0.9	$ 0	$ 0.9

Senator **Adams**. Thank you, Doctor, very much.

How well do you think NIMH is doing to keep practitioners informed about the advances of research? Is there more that could be done to see that psychiatrists, psychologists, social workers, and others are kept up to date?

Now, I mention this for a particular reason. We are in other committees dealing with the problem of drug abuse, crack, and in our part of the country we now are faced with ice, which is a cooking of methamphetamines. We want to put more money into treatment, but we have at the present time no treatment system for particularly crack and ice and—well, really not for cocaine, either.

Can you give us any statement of is there something that is potential for coming out into the field soon? We are all in agreement we are fighting a battle on the streets now with police and more money and prisons and so on, but that is never going to solve our problem.

Dr. **Pardes**. I agree.

Senator **Adams**. We have to stop people from ingesting it, that is one. But after they have ingested it, we have to do something with them. I am just asking you because you are in a particular field that can be very helpful to all of us. As we are putting money into this, we want to be able to say we are putting money into treatment and that treatment has some hope of at least stabilizing the individual.

Dr. **Pardes**. Well, my feeling is the investment in research has shown that we can produce new treatments. In fact, there is some evidence to suggest that antidepressant treatments help in a certain number of patients with cocaine abuse. What we are doing, however, is, by virtue of the increased research we have started to get in the last few years, is launch the research that will develop those new treatments.

My feeling is that we have every reason to think we will be more successful with those illness areas as we have been with others. One of the important reasons for confidence is that there has been a remarkable improvement in the overall research sophistication across biomedical and behavioral research. That is why you hear the words revolution and excitement from many different people in the scientific arena.

My feeling is we can do it in drug abuse as well if we have got the necessary resources, but that means laboratories that are modern. It means young investigators who are supported. It means bringing the best minds in. And if the best minds feel that the people in the area already are failing or not able to get support, they are not dumb; they go to other fields.

What we want to show them is this is a field we are going to make an investment, that we are going to not let other countries take over for us. And as a result, they will do the science that will address our problems.

As for your earlier question about NIMH educating clinicians, NIMH is doing that increasingly. They have got a special program now to educate clinicians about depression. ADAMHA is making increasing efforts, working with the professional associations to train clinicians and then to work with those professional associations to develop more continuing education and update programs.

The American Psychiatric Association has an enormous program now in which we work to keep practitioners updated. I think it is a legitimate concern and one that we are trying to address.

Senator ADAMS. Thank you very much for your excellent testimony.

STATEMENT OF MARTHA KEYS, VICE PRESIDENT, NATIONAL MULTIPLE SCLEROSIS SOCIETY

Senator ADAMS. Our next witness is Representative Martha Keys, former representative from the State of Kansas.

Welcome, Martha. It is nice to see you again.

Ms. KEYS. Thank you. Thank you very much, Mr. Chairman. I am very pleased to be here. Thank you for allowing me to testify before you.

I am here today as the vice president for public affairs of the National Multiple Sclerosis Society, which represents over 400,000 individuals and families affected by MS across our entire land.

Certainly, as always, people here are testifying to the choir, and your wonderful support and leadership on this issue, along with Senator Harkin and Senator Specter, has been well known, and we certainly want to thank you for that. I want to thank you for the support and funding that you have given.

I would like my testimony to be introduced into the record, though I am certainly not going to read the entire thing now, but would like to highlight a few points for you.

Senator ADAMS. Without objection, your entire testimony will appear in the record as given.

Ms. KEYS. Thank you.

Because of this investment and because of the tremendous advances that have been made, really a whole new field, neuroimmunology, has been developed and really opens the doors to the new research approaches that just a decade ago would not have been possible at all.

We feel at the National Multiple Sclerosis Society that we really must optimize this past investment and we must grasp the research opportunities that currently exist and try to bring to fruition the clinical application of that knowledge.

By statute, you here have called this, the 1990's, the decade of the brain, and it seems that now more than at any other time in the history of medical research, we have adequate fundamental knowledge to provide sophisticated studies of the nervous system.

We have a list of about seven areas that we think are essential to unlocking the keys. I will not read them all to you, but they are in my testimony. It is a long list. However, without thoroughly and completely investigating these opportunities, we feel that we will never put together the puzzle and be able to control or eradicate the disease of MS.

I know that everyone has testified for increased funding, and I have listened with great interest. It is nice to be at a hearing where everyone is speaking in a way that you can wholeheartedly support.

But I do believe that we have to remember that the National Science Foundation recently found in a report that for the first time in 14 years, private financing of research and development efforts has not kept pace with inflation, leading many to fear that as a nation, we are going to soon be lagging behind in our efforts to maintain a competitive position.

In the private sector, of course, these changes are happening at the same time that we have budget constraints and decreased support for the Federal programs. That is shown in the administration request this year, which, frankly, we were shocked at the low request.

We believe that it is just very important that we really keep on track with a plan that was supported, beginning about 2 years ago, by the ad hoc group to double the NIH funding in the next 5 years. Therefore, although we are a member of that group and support its positions, usually, we believe the $9.2 billion request by that group, which would barely stabilize funding, is not adequate.

We really believe that we should address the research opportunities that we have and fund NIH at a level of $11.5 billion. Funding at this level would allow the two research institutes that are primarily involved in MS research, which is NINDS and NAI—oh, dear, I have trouble with these acronyms, but the National Institute of Allergy and Infectious Diseases, to proceed with just a few things I would like to mention.

Restorations of funds that have just been automatically and arbitrarily cut out of the noncompeting investigator-initiated awards or the continuing awards. Full funding of 50 percent of peer reviewed, approved research grants. Now, these are not all the grants that are in, but only those which are approved as necessary and as adequate and high quality by a peer review committee.

Expansion of clinical trial efforts, and we certainly are anxious to get to that. Increased initiatives in research training. Restorations of funds that have been automatically cut from the research centers, and the expansion of intramural research programs.

In short, we think we have short changed this investment in our future too long and that the continuing dealing with policy through a numbers game needs to be stopped in this area. I can think of nothing that would be more important to our future society and our future economy than the elimination of some of these disabling diseases.

MS is a disease that strikes down young people just at the time that they are beginning to reach the peak of their productivity and contributing to the general good. There is a great deal of hope that in this coming decade some of the basic answers to this disabling disease as well as many others could be found.

PREPARED STATEMENT

I urge you to think seriously about supporting the figure that will meet the opportunities that exist, and that is the figure of $11.5 billion.

Thank you very much, Mr. Chairman.

[The statement follows:]

STATEMENT OF MARTHA KEYS

Mr. Chairman, distinguished Members of the Subcommittee, thank you for the opportunity to testify before you today on behalf the medical research programs supported by the National Institutes of Health. I am Martha Keys, Vice President, Public Affairs, National Multiple Sclerosis Society, which represents over 400,000 individuals and families affected by MS across the country.

First, to thank you for the ardent support you and your colleagues have given to the NIH and salute the tremendously productive research that is being conducted in laboratories across the country. Nothing would make me happier than to tell you that a cure for MS, one of the major disabling diseases of young adults, has been found. Unfortunately, I cannot. Therefore, I am here today to respectfully request that you increase support for these programs, and continue to keep alive the hope that a cure will soon be found.

Background

As a result of major advances in technology and the conduct of medical research, chiefly molecular biology and molecular genetics, the complex mysteries of the immune system and the structure and function of the nervous system are coming together to direct future research efforts in multiple sclerosis.

As a result of meetings held in the mid-1980's and subsequent research on the immune system and neurologic disorders, as well as research advances, it is becoming clearer to researchers that several diseases are mediated by the immune system -- in other words, they are actually regulated by that system. Included among the diseases based in the immune system are those which are autoimmune disorders, such as multiple sclerosis, believed to occur in people genetically predisposed to the disease.

In essence, your wise investment in basic research has broadened the horizon of a new field -- Neuroimmunology -- and opened the door to new research approaches that a decade ago would not have been possible. The past 5 to 10 years has created an explosion of new and innovative findings which must be pursued further if relief is ever to come to the individuals who suffer from M.S.

In order to optimize our past investment, grasp the research opportunities which currently exist, and bring to fruition clinical application of that knowledge, additional funding is needed. By statute, you have called the 1990's the "Decade of the Brain." Now more that at any other time in the history of medical research, we have adequate fundamental knowledge to pursue sophisticated studies of the nervous system. It is imperative that we support the following research.

* Molecular genetics of neurologically-based autoimmune diseases, such as MS.
* Retroviruses and their relationship to disease, such as M.S.
* Mechanisms underlying neurologically-based autoimmune disorders like MS, Interdisciplinary studies encourage interaction between basic research and important clinical endpoints.
* Basic research and support of animal models of MS.
* Enhancing the approach of immunoregulatory medications for control of disease.
* Immunopathogenesis of autoimmune disorders.
* Support for MS and other autoimmune disease tissue. This is of particular interest to the NMSS to accelerate genetic studies on individuals afflicted with MS.

Quite a list! However, without the thorough and complete investigation of these research opportunities, we will never put the total "puzzle" together and be able to control or eradicate diseases, such as MS. As you are acutely aware, MS affects primarily young people in the prime of their lives, at a period when their productiveness for the greater good of society is at its peak.

I know that many witnesses before me, and many after me are pressing for increased funding for their research interests. In responding to these requests, I encourage you to take into consideration the findings of a report released by the National Science Foundation in January. It stated that for the first time in 14 years, private financing of research and development efforts has not kept pace with inflation, leading many to fear that as a Nation, we will soon be lagging behind in our efforts to maintain a competitive position in technology. Further the report states that the private investment being supported is increasingly being shifted from basic to applied product development.

Gentlemen, these shifts and cuts in the private sector are being realized simultaneously with budget constraints and decreased funding in Federally supported programs. Unfortunately, we are also at a time in the history of medical research when greater opportunity exists than ever before.

Unfortunately, the 1991 Administration's Request did not include adequate funding for any of these initiatives. Overall, the NIH budget only received a $354 million increase, which will not even stabilize research efforts at the NIH, let alone provide for new initiatives. I recognize that many, many important programs received cuts. However, I can think of no greater contribution to our society and our economy than the eradication of disabling diseases.

In keeping with the 5-year plan developed by the Ad Hoc Group for Medical Research to double NIH funding as described in past years, the National Multiple Sclerosis Society urges the Congress to provide for NIH programs $11.5 billion, the amount that is necessary to act upon the research opportunities and needs, identified by the research community. We have short changed this crucial investment in America's future too long. Now is the time to support our priorities. Further, special emphasis should be made to fund the National Institute of Neurological Disorders and Stroke at this level in recognition of Congress' mandate to support the "Decade of the Brain."

Funding of the NIH programs at this level would allow the two Institutes involved in research on MS, the National Institute of Neurological Disorders and Stroke, and the National Institute of Allergy and Infectious Diseases to proceed with funding of high priority research programs within their specific areas of expertise. Funding at this level will provide for the following.

- Restoration of funds automatically cut from non-competing investigator initiated awards.
- Full funding of 50% of the peer reviewed, approved competing research investigator awards.
- Expansion of clinical trial efforts to include high priority initiatives.
- Increased initiatives in research training.
- Restoration of funds automatically cut from research centers.
- Expansion of intramural research programs supported by each of the Institutes.

The Ad Hoc Group for Medical Research has recommended to the Congress a figure of $9.2 Billion to stabilize the research environment. However, we believe that the tremendous research opportunities which exist warrant your support, and, therefore, request your consideration of the $11.5 Billion figure which will enable us to address these crucial initiatives.

Without funding for these important programs, I can promise you that research efforts will be slowed dramatically; young investigators will go unfunded; individuals contemplating careers in science will be turned away; and, the many individuals who suffer from life threatening and chronic diseases will continue to suffer.

Thank you again.

LETTER FROM MARTHA KEYS

April 3, 1990

The Honorable Tom Harkin
Chairman
Senate Appropriations Sub-committee for
Labor, Health and Human Services, and Education
SD 186
Washington, DC 20510

Dear Mr. Chairman:

I appreciate the opportunity that you provided me to appear before your sub-committee on March 22nd to express the National Multiple Sclerosis Society's position on the need for a major increase in funding for NIH.

Senator Brock Adams, who was chairing the hearing, asked me to provide information on the latest treatments of MS for the record.

No treatment that halts the course of the disease has been found to date, but there are a number of treatments that manage or control the symptoms of multiple sclerosis. There are two general categories of treatment for multiple sclerosis: Those aimed at the underlying disease process, and those that treat specific symptoms of the disease. In the first category are treatments aimed at the immune system, such as prednisone and other immunosuppressive drugs. Several of these shorten the exacerbations of the disease in some people.

Major advances in immunology made it possible for clinicians to test new therapies designed to have a specific effect on the immune abnormalities of MS. Three important immunosuppressive treatments were tested on chronic-progressive MS: intravenous cyclophosphamide, oral cyclosporine, and total lymphoid irradiation. Some benefit was derived with all three therapies; however, each produced significant side effects (or carried long-term risks) mandating that they be used with considerable caution. New schedules of cyclophosphamide treatment continue to be evaluated.

Copolymer I, developed in Israel during the early 70s, was finally subjected to preliminary evaluation. In the early states of MS, Cop I markedly reduced new attacks or repeat exacerbations. Its effect on chronic-progressive disease was less noticeable. There is considerable enthusiasm for further study of Cop I, and a major definitive trial will be started this year.

Interferons, natural human proteins with antiviral functions, were perhaps the most interesting agents tested during the 80s. Five major studies were undertaken on all three interferons: alpha, beta and gamma. Both subcutaneous and spinal fluid injections were used, and varied doses were tried.

The most important of these studies involved gamma interferon, which surprised everyone by stimulating new MS attacks. While this was not what was desired, nevertheless it showed that gamma interferon plays a central role in triggering exacerbations. It also suggested that if gamma interferon could be inhibited, then perhaps MS could be controlled. Since laboratory studies had shown that beta interferon inhibits the production of gamma interferon, it was decided to do a trial of synthetic beta interferon. The agent proved to be safe even when injected subcutaneously in high doses for prolonged periods. Now its effectiveness in early MS is being tested in a large, multicenter trial at 11 university centers in the U.S. and Canada.

Many scientists expect drugs that can block very specific aspects of the immune response will be developed in the near future, and it's likely that some of these will be useful for treating MS.

Treatment of MS is still mainly the province of neurologists, who are better educated in the more useful ways of managing MS symptoms than they were 10 years ago. They are using tools that have been with us for some time, but using them much more widely.

A broad range of treatments are available for specific symptoms of multiple sclerosis. These include physical therapy; drug treatments that alleviate spasticity, weakness and fatigue; orthopedic and mechanical aides; and drugs that control bladder and bowel problems.

The widespread problem of fatigue in MS is now often treated with amantadine or pemoline; some patients respond well to these drugs. The proper use of steroids in managing acute MS attacks is better understood and applied with greater skill and less risk than was previously the case.

Because the symptoms and their severity differ in different people with multiple sclerosis and from time to time in the same person, no single treatment or combination of treatments can be recommended for all patients.

Again, thank you for the opportunity to participate. We, at the National MS Society feel that our investment in basic health research is vital—not only for a positive future for individuals and families affected by MS, but indeed for the future of our entire society and economy. Please contact us if we can be of further help.

Sincerely,

Martha Keys

Martha Keys
Vice President
Public Affairs

Senator **Adams**. Thank you, Congresswoman Keys.

My only question is what is the most promising development in the treatment of MS, in your opinion?

Ms. **Keys**. When you say the treatment of MS, I cannot give you an answer to that. I do believe in terms of making the quality of lives of those who already have MS better, I do not have an answer of that. I can certainly try to provide that.

But as far as searching for the cure, I think the areas of research that are mentioned in my testimony which have to do with neuroimmunology probably present us the most immediate hope for finding the answer to that puzzle.

Senator **Adams**. Thank you very much. We appreciate your testimony, and the committee will take that, certainly, into consideration.

Ms. **Keys**. Thank you.

STATEMENT OF MYRON WEISFELDT, PRESIDENT, AMERICAN HEART ASSOCIATION

Senator **Adams**. Our next witness is Dr. Myron Weisfeldt, president of the American Heart Association.

Doctor, welcome to the committee.

Dr. **Weisfeldt**. Thank you, Senator Adams.

Cardiovascular disease and stroke remain America's No. 1 killer. Of those Americans alive, one in four currently suffer from cardiovascular disease.

The proposed 1991 budget for NHLBI, in fact, is so low that it does not cover the estimated cost of inflationary increases.

I want to amplify on Dr. Kenneth Brigham's comments on the need for funding for the specialized centers of research within the

Heart, Lung, and Blood Institute, where I believe there is a crisis situation. Again, these programs are designed to translate basic research into clinical reality.

Based upon the current proposed moneys for these programs, there will be less money in the proposed budget than in 1987, and in fact, already approved SCOR programs would be cut 25 percent from their study section allotments.

We believe, as Dr. Brigham mentioned, that not only is it bad to cut these programs, but we need to expand our SCOR program into three particular areas. The first of these areas is the area of vascular biology. From such a program, we believe, answers to problems like reocclusion of coronary arteries after balloon angioplasty, which is an enormous economic and personal problem, will be conquered. And I believe that SCOR's in vascular biology will also make significant impact on the problem of stroke.

The Hank Gathers tragedy clearly highlighted the need for programs in sudden cardiac death. The NHLBI CAS study recently identified the fact that two commonly used pharmacologic agents, in fact, kill more Americans than they save as treatment for sudden cardiac death. So clearly, we need more research into the cause, ways of identifying people at risk for sudden death, and ways of treating people and preventing sudden cardiac deaths.

We also believe that SCOR efforts in heart failure would be of great advantage to patient diagnosis and treatment.

Beyond the SCOR programs, we endorse the NHLBI's effort to implement gene therapy and bone marrow transplantation within the intramural programs, and we endorse a $1.3 billion overall budget for NHLBI.

Turning for a moment to the National Institute on Aging, cardiovascular disease affects 84 percent of Americans over age 65, and we have very little insights into the cause of atherosclerosis as it appears in Americans in elderly age groups.

As an example of this, the Office of Technology Assessment this year advocated that there was no economic advantage of measuring serum cholesterol in Americans over age 65 without evidence of heart disease.

Senator ADAMS. Excuse me, Doctor. Would you repeat that, because I got just part of it and it is one of the——

Dr. WEISFELDT. Yes; the Office of Technology Assessment report stated that for Americans over age 65 who do not have evidence at present of heart disease, that it is not economically worthwhile measuring serum cholesterol, and it is not economically worthwhile treating elevated cholesterol in that age group, reflecting the lack of basic information about the cause of atherosclerosis in older Americans.

It is on that basis that we, the Heart Association, support a $7 million special effort program within the National Institute on Aging in cooperation with the Heart, Lung, and Blood Institute to investigate the basic causes of atherosclerosis in aging, that is, in older animal models of atherosclerosis.

PREPARED STATEMENT

That includes both two initiatives from those two institutes in this area as well as a special vascular laboratory at the National Institute on Aging center in Baltimore.

That completes my testimony.

[The statement follows:]

STATEMENT OF MYRON WEISFELDT

I am Myron Weisfeldt, director of the Cardiology Division at the Johns Hopkins Hospital and president of the American Heart Association. The AHA, dedicated to the reduction of disability and death from cardiovascular diseases and stroke, works closely with related Federal research, education, and prevention programs. Since 1948, the AHA and the National Heart, Lung, and Blood Institute have been active partners in the battle against these diseases.

Cardiovascular diseases and stroke remain America's number one killer, claiming nearly one million lives each year. However, we are making progress. From 1977 to 1988, the age-adjusted death rate from heart attack and stroke fell 30.9 percent and 37.3 percent, respectively. But we must not become complacent. More than one in four Americans suffer some form of cardiovascular disease at an estimated cost in 1990 of $94.5 billion in medical expenses and lost productivity.

The AHA's ability to combat cardiovascular disease correlates directly with the level and quality of overall support of basic and clinical research and prevention efforts. The AHA continues to devote more resources for research, but we cannot win the fight alone. Sufficient federal funds are critical.

The FY 1990 Gramm-Rudman-Hollings deficit reduction target was achieved, in part, through a partial sequestration. This dangerous precedent usurps the jurisdiction of the Appropriations Committees. The sequestration and administrative reductions drove the NHLBI's FY 1990 budget down to 2.52 percent over its FY 1989 appropriation, $10.162 million below the FY 1990 request, and $18.910 million less than the FY 1990 conference allowance before adjustments.

Diseases of the heart, lung, and blood kill almost as many Americans as all other diseases combined. The NHLBI's allocation of funds should reflect this important fact. However, the NHLBI's FY 1990 increase over its FY 1989 appropriation ranked it 12 out of 13 institutes. The President's FY 1991 request places the NHLBI 11 out of 13 in proposed percentage increases.

The NHLBI has planned exciting activities for FY 1991, including new Specialized Centers of Research programs on blood vessel diseases, sudden cardiac death, and heart failure and a clinical trial on mild high blood pressure treatment. These and other projected initiatives, to continue progress against cardiovascular diseases, may not proceed due to lack of funds.

The President's FY 1991 budget of $1.113 billion for the NHLBI, a 3.7 percent increase over the FY 1990 appropriation, fails to cover the estimated cost of inflation. It provides a modest increase in research project grants and in the research management and support mechanism, but holds research centers, training, and research and development contracts constant for non-AIDS activities.

The NHLBI's Specialized Centers of Research (SCOR) programs constitute an integral component of the overall NHLBI research effort. SCORs serve as an effective means of concentrating research resources, facilities, and personnel on high priority research areas. These centers are unique in translating basic science and clinical research findings rapidly into clinical applications. SCORs multidisciplinary focus, with an emphasis on network coordination, provide a valuable complement to other NHLBI research mechanisms. However, SCORs face a crisis situation. The President's FY 1991 budget recommends the same number of SCORs, but proposes to hold constant this mechanism for non-AIDS research. Funds proposed for centers in FY 1991, $86.295 million, are less than that obligated in FY 1987. Since FY 1987, the NHLBI increased the number of centers from 60 to 64 and initiated new centers programs on sleep disorders and on cystic fibrosis, strongly supported by Congress. Budgetary constraints force the NHLBI to divert resources from ongoing center programs to support the new ones.

The proposed level budget for centers would compel the NHLBI to cut program awards by an estimated 24 to 25 percent below study section recommendations, adversely affecting center programs on hypertension, ischemic heart disease, and atherosclerosis. The latter are up for renewal in FY 1991. Projected cuts would force the NHLBI to curtail current programs, end ongoing projects, reduce staff or decrease the number of centers. The budget would require SCOR cuts when an expansion of these programs is vital to gain needed cardiovascular knowledge.

A $37.8 million increase for centers would restore projected cuts, strengthen existing centers, and support the expansion of the SCOR program in three cardiovascular areas which require additional multidisciplinary research: blood vessel (vascular) diseases, sudden cardiac death, and heart failure. This increase recommended by the AHA includes $17 million to restore existing centers to approved funding levels and $20.8 million to expand the SCOR program.

Cardiovascular diseases, often blood vessel-related (vascular), include coronary heart disease and stroke, with high incidence, serious morbidity and significant mortality. The multidisciplinary research in the prospective Vascular Biology and Medicine SCOR will enhance understanding of vascular disease and develop and improve detection, management, and prevention methods. Sudden death from coronary heart disease happens unexpectedly, within one hour of symptoms. About 60 percent of the over 500,000 heart attack deaths each year occur within the first hour. But, the factors leading to sudden death, an abnormal heart rhythm (arrhythmia), remain a mystery. The multidisciplinary collaborative focus of a Sudden Cardiac Death SCOR will facilitate the translation of basic studies of electrically active membranes into clinical diagnostic and therapeutic techniques and promote new approaches and therapies on arrhythmias. Over 2 million Americans suffer from heart failure. No cure for this condition exists and treatment remains primarily symptomatic. The origins and the molecular and cellular mechanisms of heart failure continue to be poorly understood. The prospective Heart Failure SCOR program will integrate basic research on pathophysiologic mechanisms with research on patient diagnosis and treatment.

The President's proposed level budget for research and development contracts provides resources for current clinical trials, but no new initiatives. Planned high priority cardiovascular clinical trials would be delayed or eliminated, forcing the NHLBI to postpone a large scale clinical trial to assess the efficacy of a newer class of drugs (calcium antagonists and angiotensin converting enzyme inhibitors) in reducing heart attacks in victims of mild to moderate hypertension (high blood pressure). About 61 million Americans suffer from hypertension, the most prevalent of all cardiovascular diseases, a major risk factor for heart attack, and the leading contributor to stroke. This Coronary Heart Disease Prevention in High Risk Hypertensives clinical trial may enhance treatment of hypertensives, reduce the incidence of heart attack and stroke, and decrease health care costs. A $2.6 million increase is needed for the first year costs.

Research project grants have consumed an increasingly larger portion of the NHLBI's budget. Over the years, the number of funded new and competing renewal grants has declined sharply and individual approved grants have been cut from 13 to 17 percent of full cost. The President's FY 1991 request would allow the NHLBI to award 718 new and competing renewal research project grants, but funding would have to be cut by 14 percent and 11 percent for noncompeting grants.

The President proposes a level budget for research career awards and research training. Level-funding for research career awards and training will jeopardize future research manpower needs.

The NHLBI's education and direct prevention programs are funded primarily from research and development contracts, and research management and support (RMS). The President's budget holds the contract mechanism constant for non-AIDS research, but the RMS mechanism would be increased by 5 percent to cover pay raises and other mandatory costs. The NHLBI's highly visible National High Blood Pressure Program and National Cholesterol Education Program, which complement

AHA's Heart Rx program and Physicians' Cholesterol Education Program, represent prime examples of successful public and private cooperative efforts.

The NHLBI is developing the National Heart Attack Alert Program to reduce the time between the onset of a heart attack and the victim's admission to intensive care. We support the NHLBI's efforts to assist physicians in educating patients about heart attack warning signals and symptoms and in developing emergency plans for prolonged chest pains. Most heart attack victims who die do so within two hours from the onset of signals, so time is critical. Each year, over 300,000 people die of heart attack before reaching a hospital. Half of all heart attack victims wait more than two hours before going to an emergency room. Prompt care dramatically reduces heart damage. About 80 percent of heart attack survivors return to work within three months. The AHA is working to expand awareness in this area.

The NHLBI programs have been highly successful in the battle against cardiovascular diseases due to the maintenance of research program balance. Basic research is the cornerstone of its programs. But over the years, the Institute's staff, Advisory Council and the scientific community have also stressed the importance of other program mechanisms, including clinical trials, population studies, Specialized Centers of Research, national research and demonstration centers, research career and training awards, research and development contracts, and education and direct prevention programs. This carefully balanced approach has contributed to the success of the NHLBI's programs and has enhanced its reputation as a world-wide leader in cardiovascular research.

Based on a review of the NHLBI's critical needs, the AHA recommends a FY 1991 appropriation of $1.308 billion for the NHLBI, a 22 percent increase over its FY 1990 budget. It will allow the NHLBI to continue current research momentum and to begin several initiatives which have a high potential for success. This percentage increase conforms with the Ad Hoc Group For Medical Research Funding's suggested increase for the entire National Institutes of Health.

The NIH is the leading Federal biomedical research agency, with the NHLBI as the largest source of cardiovascular research. Regarding the proliferation of NIH institutes, the AHA is not opposed to the establishment of new institutes, but believes that there must be a better process to evaluate such needs.

The President's NIH request falls short of maintaining current services. We support the Ad Hoc Group's recommendation of $9.237 billion for the NIH, which would provide a modest growth over current services, allowing full support of both research project grants, existing research centers and additional centers. This amount would fully fund a modest 30 percent of competing research project grant applications, provide full tuition for 12,020 National Research Service Award trainees, and support first year expenses of key unfunded clinical trials.

Thank you for this opportunity to appear before your Subcommittee.

Senator ADAMS. Thank you very much, Doctor. I asked the question because it has become a matter of some contention. I am not saying that people should not treat cholesterol problems, but it has become a gigantic industry, and now there seems to be a little question as to whether its connection to atherosclerosis is as direct as originally assumed.

Dr. WEISFELDT. Trust me and my scientific colleagues that for middle-aged American males, there is absolutely no question as to the importance of cholesterol and diet in terms of cardiovascular risk and survival. For every 1-percent reduction in cholesterol, there is a 2-percent reduction in heart attack rate.

We do not know whether those conclusions drawn from populations and studies of middle-aged males apply straightforwardly to the older segment of our population and to females, and the reason we do not know is we have not done enough research to find out.

Senator ADAMS. What was the age you mentioned?

Dr. WEISFELDT. Over age 65. The OTA assessment is the Medicare population, over age 65.

Senator ADAMS. Thank you very much, Doctor, for your testimony.

Dr. WEISFELDT. You are welcome.

STATEMENT OF SUZANNE PATTEE, CYSTIC FIBROSIS FOUNDATION

Senator ADAMS. Our next witness is Robert K. Dresing, the Cystic Fibrosis Foundation.

Ms. PATTEE. Hello, Senator Adams. I am here today for Bob Dresing, president of the Cystic Fibrosis Foundation. I have submitted his testimony for the record.

Senator ADAMS. Without objection, the entire testimony will appear in the record as though given, and we would be happy to receive you and your testimony.

Ms. PATTEE. Great. Wonderful.

I am Suzanne Pattee, and I have cystic fibrosis. I want to thank you and your predecessors for your investment in CF research.

I am pleased to tell you the scientists have discovered the gene and the protein that cause cystic fibrosis. This discovery brings tremendous hope for the future.

I am the only one out of five children born with this fatal disease. When I was born, my parents thought that I would only live to be 5 years old. They thought they would never see me grow up. Today the life expectancy is 27. I am 26. But I am optimistic about my future.

I am working 30 hours a week for the Cystic Fibrosis Foundation, I am going to law school at George Washington University and I am getting married in May. I have seen and benefited from past research advances.

With the recent discovery of the gene, science promises a much brighter future. Never before have I dared to think that I may have children and watch them grow old.

The researchers believe we can conquer this disease in the lifetimes of people who have CF now. However, the huge potential today in biomedical research is threatened because the NIH may not get the funds it needs to accomplish its goals. As someone whose future depends upon medical research, this is devastating.

Our research centers are facing cuts as high as 23 percent, which will slow the research progress and eliminate some projects entirely. And only one out of four research projects deemed by the NIH to be worthy of support is now getting funding.

I am proud of the Cystic Fibrosis Foundation and how we are stimulating science. We are creating innovative programs with the NIH. We have invested $27 million creating our own research centers, and we have invested another $1 million in projects that the NIH has approved but cannot fund.

But all of these efforts are just a finger in the dam. Ultimately, the foundation cannot replace the NIH. That is why it is imperative that you support the recommendations of the ad hoc group for medical research funding and the National Health Council.

We need your support for research centers, we need your support for scientific training and we need your support for animal research. With this investment, we will be able to tap the potential of the gene and its protein. This is the only way we can hope to control and cure this disease.

I understand that there are lots of demands on Federal money today, but there is no better investment than biomedical research. It is an investment in people's lives.

Today we need treatments that will help reduce the staggering cost of CF. A small investment in CF research now will save millions in health care costs in the future.

PREPARED STATEMENT

As I have said, I am investing in my future. I ask you to invest in the future of the NIH and in the future of every person who has cystic fibrosis. Scientists say this disease does not have to be fatal, and with your support, it will not be.

Thank you.

[The statement follows:]

STATEMENT OF ROBERT K. DRESING, PRESIDENT AND CHIEF EXECUTIVE OFFICER, CYSTIC FIBROSIS FOUNDATION

Mr. Chairman and Members of the Subcommittee:

My name is Robert K. Dresing and I am president of the Cystic Fibrosis Foundation (CFF). I want to express my gratitude to you for believing in the work of the cystic fibrosis researchers as they struggled to identify the gene and the protein that cause cystic fibrosis (CF). Thanks to the funds you directed toward this research, we can now celebrate and move forward from these tremendous achievements. Most significantly, we can now tell the thirty thousand children and young adults with CF, including my 23-year-old son, Rob, that their future is within our reach.

The discovery of the CF gene and protein last August symbolized all that is good about biomedical research. The collaboration of outstanding scientists from numerous institutions, particularly Drs. Francis Collins, Lap-Chee Tsui and John Riordan, with years of support from the National Institutes of Health (NIH) and the CFF, brought about these discoveries.

Our diligence--and yours--in selecting and investing in scientific winners paid off. Now again, we must take bold steps to translate the findings into a clear understanding of the basic defect and its possible treatment. It was just a few decades ago that parents were told their children would live only long enough to attend kindergarten. Today, parents are grappling with the possibility of a future free from cystic fibrosis.

This dream cannot come true without your continued investment in biomedical research. Today's limited federal dollars threaten to undermine the goals of the NIH, one of the most productive enterprises in this country. With the weakening support for the NIH, we face a powerful dam ready to burst--a flood of scientific opportunities that may be washed beyond our reach.

Our own CFF research centers offer a symbol of the importance of a solid framework for bringing research advances. We have learned first-hand that the sum is much bigger than the parts, and that the results of the research centers are far greater than a group of related research grants. Since your mandate, we have invested more than $27 million in establishing successful centers, nine of which have since earned support through the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) and the National Heart, Lung and Blood Institute (NHLBI). Your foresight in channeling these funds allowed the centers to lay the groundwork for identifying the faulty gene and protein.

While research centers may seem like a reasonable target for cuts because of their ostensibly large amounts of funding, such downward negotiations, as high as 23 percent, weaken their very purpose. Centers are forced to let highly trained and committed researchers go; progress is slowed as scientists minimize research goals to offset reduced dollars.

Other cracks are seen inside and outside of the NIH. The strength of the Intramural Program--the source of many great CF research leaders--is threatened by lack of support despite our best efforts to expand fellowships and implement an extensive lecture series on CF research advances. Furthermore, across the country, the low award rate for NIH-approved research projects is discouraging even the brightest scientists. Currently, only one in seven of the approved, high-quality projects receives funding. How low can the award rate go before no one will apply?

The Foundation has tried to fill in the gaps by creating the CFF/NIH Research Award--to our knowledge, the first award of its kind. Now in its second year--at a cost to us of more than $1 million--this program is providing CFF funding for outstanding NIH-approved projects. We are also combining forces with the NIH to create another unprecedented program--a joint request for applications to probe the CF gene and the CFTR protein.

Ultimately, though, this effort on our part is merely a finger in the dam. Moreover, we must emphasize that we cannot continue to supplement the NIH's programs and support our own research simultaneously. Our efforts to instigate pilot and feasibility projects and to foster young investigators who can bring new ideas and new talents to CF are the backbone of tomorrow's research successes.

Indeed, to guarantee future research progress, there must be strong federal support from basic research discoveries to the development of treatments. One example of building on basic findings is the drug, amiloride, which shows signs of thinning the thick, sticky mucus to help people with CF avoid lung infections. Ways to replace or correct the CF gene--gene therapy--are also being explored. Already in the pipeline are clinical trials to investigate new treatments. Hundreds of CF patients are currently helping to test steroids, ibuprofen, aerosolized antibiotics, and new uses of oral antibiotics. By helping people with CF before health problems multiply, these treatments could lead to enormous savings.

A strong foundation for research would be incomplete without appropriate studies on animals. Despite the widespread scientific commitment to the ethical use of animals in research, scientific efforts in this country are being undermined by animal rights activists. Headlines show intimidation of scientists and damage to research labs draining millions of dollars from already limited research funds. This movement may be the most destructive force to biomedical research in this century. For CF, this is occurring at a time when we finally have scientists working to develop a transgenic mouse--an animal model which would enable testing of the basic defect and evaluation of new therapies. We urge you to take a leadership role in ensuring that animal research is not stifled by special interest groups who disregard the future of our children.

No one expects the federal government to meet every research need. However, proven programs like those of the NIH deserve your full support. Your reliance this past year on partial sequestration to finalize budget negotiations led to an unacceptable cut of $107 million to the NIH's budget. Besides undermining people's trust in your leadership, this type of cut detracts from the scientists' ability to carry out their projects and their confidence in planning the next research steps.

While we recognize the importance of constraining the federal budget, the situation demands change, especially at this time when we can take advantage of the peace dividend and shift our budget priorities from military weapons to our people's health.

We urge you to support the recommendations of the NIH experts and the National Health Council in providing $11.6 billion to fully meet the current scientific needs at the NIH. At a minimum, $9.2 billion is necessary for the NIH to fully restore funds for research centers and new grants, as recommended by the Ad Hoc Group for Medical Research Funding. These investments offer one of the most promising ways to bring down the skyrocketing costs of health care, which will soar to $661 billion in the coming year. For CF alone, research offers the chance to eliminate the more than $500 million this disease costs each year.

While we cannot assume the role of the NIH, we will continue to ask the NIH where we can help. In turn, we ask you to strengthen support where it can bring the greatest return: our children's lives.

Senator ADAMS. Thank you very much for your testimony. We appreciate it, and that of Dr. Dresing will appear in the full in the record, and congratulations to you.

Ms. PATTEE. Thank you.

STATEMENT OF WILLIAM T. SCHMIDT, WASHINGTON COUNSEL, AMERICAN DENTAL HYGIENISTS ASSOCIATION

Senator ADAMS. Our next witness is William T. Schmidt, Jr., Washington counsel for the American Dental Hygienists Association.

Mr. SCHMIDT. Good morning, Mr. Chairman.

Senator ADAMS. Good morning, Mr. Schmidt.

Mr. SCHMIDT. The president of ADHA, Mary Alice Gaston, had hoped to be here today but had a scheduling conflict. As has already been announced, my name is Bill Schmidt and I serve as Washington counsel to ADHA. I will summarize the recommendations contained in our longer statement, which we have submitted for the record.

The American Dental Hygienists Association represents 30,000 members across the country dedicated to assuring the highest level of preventive dental care. Originally formed to develop communication and mutual cooperation among hygienists, ADHA today serves as an advocate for dental hygienists at the Federal, State, and local levels.

Mr. Chairman, dental hygienists play a vital and cost-effective role in the delivery of oral health care services, performing numerous preventive and therapeutic services. Dental hygienists are involved in direct patient care, including patient education, review of medical and dental histories, formulation of health promotion activities, and initial therapy recommendations.

ADHA firmly believes that continued research at NIH is critical to the future of prevention. Indeed, in identifying the causes of preventable dental diseases and the appropriate strategies to combat these maladies, the National Institute of Dental Research has helped to revolutionize our knowledge and provision of dental health care.

Despite many successes and last year's increase in funding for the Institute, funding for NIDR has not been commensurate with the research need. While the administration's fiscal year 1991 budget recommends a modest increase for NIH and NIDR, it is simply not sufficient to maintain current research momentum.

The ADHA, accordingly, endorses a budget of $210 million for NIDR, a budget which would allow NIDR to capitalize on scientific opportunity. ADHA also recommends $9.2 billion for all of NIH as recommended by the Ad Hoc Coalition for Medical Research Funding.

In addition, ADHA recommends that the appropriation for the Centers for Disease Control include funds to allow the director of the Center for Prevention Services to allocate $5.5 million for the dental disease prevention activity. This figure includes an appropriation of $2 million to fund adult oral health activities and $2 million for a program to detect, prevent and treat oral cancer.

ADHA also joins the American Society of Allied Health Professions in calling for an appropriation of $6 million for allied health professions programs in fiscal year 1991, as authorized in the Health Professions Reauthorization Act of 1988. This figure contains $2 million for traineeships for advanced training of allied health personnel, ~~$2 million~~ for allied health grants and contracts and $2 million for a new loan repayment program for allied health personnel.

PREPARED STATEMENT

The 30,000 members of the American Dental Hygienists Association appreciate the important contributions this committee has made to improving the quality and availability of dental health care services throughout the country. We sincerely hope that this committee will continue to support preventive health programs as the most responsible approach to a long-term reduction in national health care expenditures.

Thank you.

[The statement follows:]

STATEMENT OF WILLIAM T. SCHMIDT

The American Dental Hygienists' Association ("ADHA") appreciates this opportunity to present its recommendations regarding FY 1991 Appropriations for the Department of Health and Human Services ("HHS"), and in particular, the National Institute of Dental Research ("NIDR"). Organized in 1923, ADHA represents 30,000 members across the country dedicated to assuring the highest level of preventive oral health care. Originally formed to develop communication and foster cooperation among hygienists, ADHA today serves as an advocate for dental hygienists at the federal, state and local levels.

As licensed providers, hygienists are responsible for providing services for prevention and treatment of oral disease such as dental caries and periodontal disease. Notably, dental hygienists play a vital cost-effective role in the delivery of oral health services.

THE STATE OF AMERICAN DENTAL HEALTH

Our nation has made significant strides in oral health. Indeed, research scientists suggest that elimination of most major dental diseases may be possible within the lifetime of oral health professionals now practicing. The most recent national survey conducted by NIDR regarding adult oral health indicates that America's teeth are in better shape than ever.

Nonetheless, a great deal remains to be done, as we are still far from the ultimate goal of total prevention. Indeed, the dental hygienists' role as the lead advocate, spokesperson and educator in preventive oral health care is an indespensible element in the quest for total prevention.

NATIONAL INSTITUTE OF DENTAL RESEARCH ("NIDR")

Founded in 1948, NIDR has helped to revolutionize our knowledge and provision of dental health. In identifying the causes of preventable dental diseases and the appropriate strategies to combat these maladies, NIDR has led the way. Despite many successes, and last year's increase in funding for the Institute, funding for NIDR has not been commensurate with the research need. A budget for FY 1991, which would allow NIDR to capitalize on scientific opportunity, would provide NIDR with $210 million for the upcoming fiscal year.

While the Administration has in fact proposed an increase of 3.7 percent for the overall NIH budget - exclusive of AIDS-related support - the Department of Health and Human Services ("HHS") estimates that, for the third consecutive year, significantly fewer new and competing research grants would be funded in FY 1991. To make matters worse, NIH has been forced to reduce the dollar amount of grant awards by an average of 12.5 percent. Moreover, only 3 out of 10 approved research grant applications at NIH will be funded in FY 1991. At NIDR, the Administration's proposed 3.5 percent increase would provide funding for only 577 research grants, 22 (or 4 percent) fewer than FY 1990.

INTERIM STUDY GROUP ON DENTAL ACTIVITIES

ADHA supports the recommendations contained in the Interim Study Group on Dental Activities report entitled Improving the Oral Health of the American People: Opportunity for Action. These recommendations include the establishment of a focus for oral health activities within HHS with clearly visible administrative and policy responsibilities; establishment of a formally chartered Advisory Committee to assist the individual serving as the focus for oral health activity; and establishment of a strong, clearly identified, oral health presence in any HHS agency which regularly conducts oral health activities.

TITLE VII OF THE PUBLIC HEALTH SERVICE ACT

ADHA joins the American Society of Allied Health Professions in calling for an appropriation of $6 million for allied health professions programs in FY 1991, as authorized in the Health Professions Reauthorization Act of 1988 (P.L. 100-607). This figure contains $2 million for traineeships for advanced training of allied health personnel, $2 million for allied health grants and contracts, and $2 million for a new loan repayment program for allied health personnel.

CENTERS FOR DISEASE CONTROL

The Dental Disease Prevention Activity ("DDPA") funded through the Centers for Disease Control ("CDC") is a vital support mechanism for state dental health programs. The DDPA provides a national focus for the control and prevention of oral diseases such as dental caries, periodontal disease, and oral cancer.

Although the DDPA is not a line item in the President's FY 1991 budget proposal, the CDC appropriation should include funds to allow the Director of the Center for Prevention Services to allocate $5.5 million for the DDPA. This figure includes an appropriation of $2 million to fund adult oral health activities, and $2 million for a program to detect, prevent, and treat oral cancer.

CONCLUSION

The 30,000 members of the American Dental Hygienists' Association appreciate the contribution this Committee has repeatedly made to improving the quality and availability of oral health care services throughout this Nation. We hope that the Committee will continue to support preventive health programs as the most responsible method for long-range reduction in national health care expenditures. Again, we appreciate the opportunity to present our views.

Summary of Recommendations:

The American Dental Hygienists' Association ("ADHA") recommends that, for FY 1991, the National Institute of Dental Research ("NIDR") receive an appropriation of $210 million. This funding request is consistent with the overall recommendations for the National Institutes of Health ("NIH") of the Ad Hoc Coalition for Medical Research Funding which recommends $9.2 billion for NIH overall in the upcoming fiscal year. ADHA strongly endorses the Ad Hoc Committee Recommendations. ADHA also supports an appropriation of $6 million, as authorized in P.L. 100-607, for allied health loan repayment, advanced training, and grants and contracts.

ADHA supports enactment of S. 1552, The Allied Health Professionals Promotion Act of 1989, to bolster those allied health professions experiencing the most acute personnel shortages, and the enactment of S. 1606, the Disadvantaged Minority Health Improvement Act of 1989, which aims to increase the number of disadvantaged minority persons serving in the health professions for the purpose of improving the access of other such individuals to health services. ADHA fully supports the recommendations contained in the Interim Study Group on Dental Activities report Improving the Oral Health of the American People: Opportunity for Action.

In addition, the Congress should indicate its desire that the Director of the Center for Prevention Services at the Centers for Disease Control ("CDC") fund the Dental Disease Prevention Activity ("DDPA") at $5.5 million through the Director's discretionary budget.

Senator Adams. Thank you very much.

I have just one question. What is the estimated current need and projected need for dental hygienists, as opposed to the current supply?

Mr. Schmidt. Mr. Chairman, that is a good question. Unfortunately, we are in a position right now where not a good deal of reliable data exists on that. We have attempted, the ADHA has, to conduct its own studies of that. As of yet, we do not have any firm evidence of a shortage, but there is a critical need for better, more reliable information, I think, across the board for allied health professionals.

Senator Adams. Thank you very much. We appreciate your testimony this morning.

STATEMENT OF JACK B. KINSINGER, THE AMERICAN ASSOCIATION OF COLLEGES OF OSTEOPATHIC MEDICINE

Senator Adams. Our next witness is Dr. Jack B. Kinsinger, American Association of Colleges of Osteopathic Medicine.

Dr. Kinsinger.

Dr. Kinsinger. Thank you, Senator Adams, and the staff for permitting us this privilege of speaking our position. My name is Jack Kinsinger. I am president of the Chicago College of Osteopathic Medicine, and I am here representing the 15 colleges of osteopathic medicine in the United States which are formed in an organization called the American Association of Colleges of Osteopathic Medicine. I have summarized our positions—complete statement, which has already been submitted for the record.

Senator Adams. Without objection, your full statement will appear in the record as though given.

Dr. Kinsinger. Thank you Senator. Senator, I would like to address three key areas: the education of primary care physicians, the delivery of health services in rural and other underserved communities and the care of the elderly. Each of these is a major activity and goal of our osteopathic colleges, and we are currently supported by one or more health professions education grants under title VII.

As you know, there is still a very bad distribution in an insufficient number of primary care physicians in this country. Our osteopathic colleges emphasize the preparation of the primary care physician. Federal grant programs, which support the training of family medicine and general internal medicine, are invaluable for addressing this national need and your continued support is essential if our strong efforts to increase the numbers and the quality of primary care practitioners is to be sustained.

Our osteopathic colleges realize that providing individuals with the basic family practice skills and opportunities to train in rural clinics is critical to solve the health needs of our rural and underserved areas. Students of my college train in family practice clinics, for example, in downstate Illinois, combining service to patients, together with education and the special needs of rural people.

Ten of the osteopathic colleges participate in the Area Health Education Center grants, the AHEC grants, and work with many rural and underserved populations through these interdisciplinary programs. We believe full funding of the AHEC program and other rural initiatives will help keep our rural health programs active and intact.

My own college has integrated and mainstreamed geriatric medicine into the third- and fourth-year courses of our program, and our center on aging provides leadership in geriatric medicine. And we believe that rotating students through geriatric services assures that our graduates are well trained to care for the elderly patients.

Finally, federally based students assistant programs are critical to many of our students, especially the HEAL program. At our institution, 380 of the 437 medical students receive financial aid. And in fact, the kind of student we attract that goes into family practice medicine comes from an economic class that needs that support. Any reduction in these loan guarantees could seriously affect perhaps their ability to continue with their education.

PREPARED STATEMENT

The National Health Service Corps is another important source of support, and those kinds of individuals do tend to go into the underserved area.

We thank you very much for this opportunity, and I will be happy to answer any questions.

[The statement follows:]

STATEMENT OF JACK B. KINSINGER

Mr. Chairman and Members of the Subcommittee:

My name is Jack Kinsinger, Ph.D. I am President and CEO of the Chicago College of Osteopathic Medicine and a member of the Executive Committee of the American Association of Colleges of Osteopathic Medicine (AACOM). I am pleased to present the views of the fifteen member colleges of AACOM on fiscal year 1991 funding for federal programs to support the education of health professionals.

I would like to address three areas in which the osteopathic medical colleges and the federal government have formed a successful partnership. These are the education of primary care physicians, the delivery of health services in rural and other underserved communities and the care of the elderly. Each is a major goal of the colleges and is supported by one or more health professions education grants under Title VII of the Public Health Service Act.

There continue to be shortages of primary care physicians. For example, since 1981, the number of federally designated primary medical care shortage areas has increased by over one third. Federal grant programs that support family medicine and general internal medicine training are invaluable to addressing these needs. Your continued support for these programs is essential to the efforts of medical education to train primary care physicians.

Several of our colleges, including my own in Illinois, are dedicated to meeting the need for primary care physicians. For example, the Ohio University College of Osteopathic Medicine and the West Virginia School of Osteopathic Medicine were both expressly charged by their state legislatures to train primary care osteopathic physicians to practice in the medically underserved areas of those states. The Texas College of Osteopathic Medicine and the School of Osteopathic Medicine of the University of Medicine and Dentistry of New Jersey have similar goals, which are shared by all the osteopathic medical colleges. Federal funds help support this mission.

Ten of our fifteen schools have been, or currently are, key partners in Area Health Education Centers (AHEC). This important multi-disciplinary program helps our Ohio college, for example, fulfill its legislative mandate by providing medical care to the rural, underserved areas of southeastern Ohio. Other colleges also participate in AHEC grants. The Southeastern College of Osteopathic Medicine in Florida provides medical services to migrant and rural families through two AHECs. The College of Osteopathic Medicine of the Oklahoma State University directs a statewide, interdisciplinary AHEC. We ask for full funding of the AHEC program, as well as for the separate initiatives for border areas and areas with special needs (Health Education and Training Centers) and the Interdisciplinary Training for Rural Areas program. These separate programs have their own distinct objectives. Thus, AHEC funding should not be diluted to support them. Each program should continue to receive its own appropriations.

The colleges of osteopathic medicine realize that providing individuals with the basic skills and interest in practicing in rural health is essential to solve the health needs of rural, underserved areas. As an example, at the Texas College of Osteopathic Medicine, students rotate through rural clinics in Justin and Godley, Texas, combining service to patients together with education in the special needs of rural people. Students may train with rural physicians located in small communities throughout Texas.

Because osteopathic medical colleges are often small, they must rely on the active participation of the federal government to keep these rural programs alive. Especially important is full funding of the rural interdisciplinary training programs and the Office of Rural Health Policy`s research centers.

My own college has integrated geriatrics into a number of its clinical courses. Between required and elective courses, our students receive extensive experience with geriatric patients. Our Center on Aging provides leadership in geriatrics in the Chicago area. Rotations of geriatric services assure that the graduate of the Chicago College of

Osteopathic Medicine has been well grounded in caring for the elderly patient.

With the increased aging population, it is more important that the programs of geriatric education be expanded, not reduced. Federal assistance is essential to develop geriatric departments at our schools and to support the programs now underway. We encourage the subcommittee to fully fund geriatric training and education programs in the Department of Health and Human Services.

Many of our senior students report parental income of less than $10,000 and some 40% come from families with incomes less than $30,000. Federal student assistance programs are critical to them.

The HEAL program is extremely important. As other federal student aid programs have declined in size, HEAL loans have become increasingly important. Any reduction in loan guarantees could seriously affect the ability of many of our students to continue their education.

The National Health Service Corps is another important source of student support. We urge full funding for scholarships and loan repayments and are encouraged by the President's proposal for this program. We view this program as crucial to efforts to improve medical care in shortage areas by helping the students and physicians who have an interest in primary care in these areas. We are working with the authorizing committees to encourage the granting of awards on a single year, rather than multi year basis, in order to increase the number of awards.

Of special importance is continued strong support of special emphasis programs for minorities and disadvantaged students. Programs such as the Health Careers Opportunity Program (HCOP) and the Scholarship Program for Students of Exceptional Financial Need (EFN) have been markedly successful and beneficial to colleges of osteopathic medicine in increasing underrepresented minority enrollment. For example, over the last three years, there has been a 43% increase in total enrollment of underrepresented minorities, and a 91% increase in first year enrollment. These targeted Federal funds are crucial in helping us attract and support committed minorities who will graduate and help solve the imbalances in access to various population groups in this country.

AACOM appreciates all the support that Congress has given to these programs and our colleges. We ask you to examine an emerging issue -- the ability of small medical schools, such as many of our colleges, to sustain their academic health. If we are to maintain or strengthen our efforts to train primary care physicians, we must be able to renovate and expand our academic facilities. Federal assistance for a portion of this effort would be welcome. We urge you to ask the Department of Health and Human Services to review this problem, explore solutions in existing programs and make recommendations back to you for further action on possible new initiatives. We do not need a massive construction program, but targeting funds to schools with an established primary care emphasis could be very helpful. We are very mindful of the current federal budget deficit and our requests are modest ones. We believe that our schools have made excellent use of these federal funds to help achieve national health priorties. Your continued involvement in our activities will, we believe, pay large dividends.

Mr. Chairman, the members of AACOM deeply appreciate the support this subcommittee has given to these very important programs. That support has contributed to our efforts to produce primary care physicians who will practice in small, underserved communities, and meet the needs of America's elderly, particularly in rural areas. We thank you for your past support and urge your continuing endorsement of these programs and support for the fullest possible funding.

Senator **Adams**. Thank you, Doctor. On the next-to-the-last page, you mention—of your testimony—you mention the National Health Service Corps. Now, I am a member also of the Labor Committee, and what are your recommendations with regard to the two methods we use. Which do you think is the better with limited resources for us to use? The funding of loan repayment and scholarship slots are the two ways that we do it now.

Dr. **Kinsinger**. The 1 year or the 3 years?

Senator **Adams**. Yes.

Dr. **Kinsinger**. Well, we would prefer to increase the numbers and go to the 1-year program.

Senator **Adams**. Go to the 1-year program?

Dr. **Kinsinger**. And increase the numbers.

Senator **Adams**. And increase the number of slots?

Dr. **Kinsinger**. Yes, sir; we take a number of students from that program into our programs as a postdoctoral training, and they support many of the clinics within the inner city. So we find that an excellent program.

Senator **Adams**. Well, we are very concerned about that in Labor and I personally am very concerned because a number of my more rural cities, I mention particularly, Yakima and Wanachee, and some of the others in the State of Washington, where we have a great many small cities. We have an enormous need for the treatment of people. We are lacking in both the rural hospital availability and, in particular, the rural clinic availability and doctors who are willing to remain in that area, so that is the reason for my question.

If you wish to submit additional information, we would be pleased to receive it because both the authorizing committee and this appropriating committee are trying to determine how we can increase the availability of medical services in the rural and nonurban areas.

Dr. **Kinsinger**. We would be pleased to make a statement for you. Thank you.

Senator **Adams**. Thank you very much.

STATEMENT OF RAYMOND FONSECA, DEAN, SCHOOL OF DENTAL MEDICINE, UNIVERSITY OF PENNSYLVANIA, PHILADELPHIA, PA, ON BEHALF OF THE AMERICAN ASSOCIATION OF DENTAL SCHOOLS

Senator **Adams**. Our next witness is Dr. Raymond Fonseca, dean of the University of Pennsylvania School of Dental Medicine, of the American Association of Dental Schools.

Doctor, welcome.

Dr. **Fonseca**. Thank you sir. As you stated, I am Dr. Raymond Fonseca, and I am dean of the school of dental medicine at the University of Pennsylvania and I am here today representing the American Association of Dental Schools.

Mr. Chairman, I would first like to discuss the pressing need to provide funding for the reimbursement of costs providing all health care to AIDS patients. As dean of an institution that treats a large AIDS patient population, I can tell you that the Federal Government is not providing assistance to meet our unreimbursed costs.

Many of the first physical signs of AIDS are found in the mouth. Therefore, a dentist is often the first to diagnose the disease and refer the patient for care. Dental schools and hospital dental programs that become known as referral centers for AIDS patients risk serious fiscal problems because many of the patients they serve have no money and no insurance coverage, while requiring more complicated treatment needs than the average dental patient.

It is important to remember that Medicaid and Medicare coverage for dental services is very limited, or simply unavailable. We estimate the dental schools and hospital dental programs are providing $11.5 million per year in unreimbursed oral health care costs for these patients.

We urge an appropriation of $5 million in fiscal year 1991 to initiate a grant program to partially offset these unreimbursed costs. This would alleviate some of the financial burden faced by these treatment centers.

The other appropriations issue I wish to mention this morning concerns the need to increase support for general dentistry programs. These residency programs train dentists in the skills necessary to provide comprehensive care to a wide variety of patients, including the elderly, the handicapped and the medically compromised.

Upon completion of this training, general dentistry residents can treat patients requiring more complex care which is especially important in rural and underserved areas, where costs or distance makes referral to specialists impossible. In rural areas, these specially trained general dentists can provide a much broader scope of patient care, since the specialists are not available.

We reiterate our appreciation for this subcommittee's efforts in securing an increased appropriation for this program in fiscal year 1990. This increased funding created approximately 59 new general dentistry residency positions across the country. However, demand for this type of training continues to grow. Current funding at slightly under $4 million is still inadequate to meet the need for these residencies. Many programs continue to be approved, but remain unfunded.

For example, the University of Iowa's application to expand its general dentistry program was approved but unfunded. We understand, however, that it is on the top of the list to be funded should appropriations be increased.

Further, the University of Washington's general dentistry residency application was approved, but only funded at the 50 percent level. Additional funding would allow the University of Washington to fully fund its program.

Our school is planning to prepare an application for the next grant cycle. However, our chances of receiving grant support are extremely limited if funding is not increased. Without Federal support, it is extremely difficult to create new programs because of the lead time needed for these programs to become self-sufficient.

Therefore, we urge the subcommittee to provide a general dentistry appropriation of $6 million is fiscal year 1991. Incidentally, this amount is well below the fiscal year 1991 authorization level of $8 million.

PREPARED STATEMENT

Mr. Chairman, we would ask that our full written statement be made a part of the record. I thank you for this opportunity to testify. I would be pleased to respond to any questions that you may have.

Senator **Adams**. Without objection, your full statement will appear in the record as though given.

And I have one question. About how many more residencies would the full $6 million funding produce and out of that, how many more practicing dentists would be available?

Dr. **Fonseca**. I am going to have—I will submit that for the record. I will have to get that information.

Senator **Adams**. I will be happy to submit it for the record. We would like to receive that information.

And we are very supportive of that program because, once again, we are trying very hard to see that all of our citizens receive at least basic care and very often, and I refer to the rural areas, we are only now beginning to see this. So we do want to see this funded, and we do want to see people moving into those areas. Thank you very much, Dr. Fonseca.

[The statement follows:]

STATEMENT OF RAYMOND FONSECA

I am Dr. Raymond Fonseca, Dean of the School of Dental Medicine at the University of Pennsylvania. I appear today on behalf of the American Association of Dental Schools ("AADS), which represents all of the nation's dental schools as well as advanced education, hospital and allied dental education programs.

I am pleased to have the opportunity to present AADS's FY 1991 funding recommendations for health professions training and research programs especially important to dental education. We deeply appreciate the support this subcommittee has given to these programs in the past. The funding you have provided has made possible tremendous progress in dental education, research, and oral health care.

During the last decade, great strides have been made in the field of dentistry that have provided a savings of approximately $3 billion annually in decreased costs to the nation's citizens. Important accomplishments have been made not only in the most common dental diseases (tooth decay and periodontal disease), but also in research contributions that go far beyond the dental field. Today, dentists are researching and treating complex oral diseases as well as oral responses to systemic diseases. Dentists are treating more medically compromised patients: individuals suffering from AIDS; patients suffering from diseases such as cystic fibrosis, diabetes, and rare or so-called "orphan" diseases such as ectodermal dysplasia and Sjogren's syndrome; elderly patients with their special needs; individuals who suffer oral complications because of cancer chemotherapy or radiation to the head or neck; patients with primary oral conditions such as oral cancers and certain chronic facial pain conditions; and patients who need major facial reconstructive surgery. Our funding requests for FY 1991 reflect the expanding role of dentistry and the changing nature of the profession. Continued advances depend on additional funding for dental research as well as increased support for dental education to upgrade curriculum, develop faculty, and train students for tomorrow's challenges.

Acquired Immune Deficiency Syndrome (AIDS): There is a pressing need to provide funding for the reimbursement of costs of providing oral health care to AIDS patients. As dean of an institution that cares for a large AIDS patient population, I can tell you that the Federal government is not providing assistance to meet our unreimbursed costs. As a group, AIDS patients suffer a high incidence of oral disease. Many of the first physical manifestations of HIV infection are found in the oral cavity. As a result of the immune system breakdown that occurs, AIDS patients are more susceptible to very severe oral herpes, rampant fungal diseases, hairy leukoplakia, as well as oral disease found only in patients who suffer from AIDS, including an extremely painful form of gum disease that frequently involves complete oral tissue breakdown with exposure of the bone. Severe pain in the oral cavity is frequently the symptom that leads these patients to seek care; therefore, a dentist is often the first diagnostician to see the AIDS patient.

Dental education institutions that become known as referral centers for AIDS patients risk serious fiscal problems because the patients they serve have complicated treatment needs, requiring more resources than the "average" dental patient. Moreover, unlike medical coverage, oral health care is not covered under many private insurance programs and is seldom covered for adults under Medicaid. Last year dental schools and clinics across the country were contacted by AADS regarding these unreimbursed costs. Based on that informal survey, AADS estimates that more than $11.5 million would be required to offset costs of providing oral health care to AIDS patients at dental education institutions.

In recognition of this pressing need, the 1988 Health Professions Training Act established a new Section, "Training with respect to AIDS." Subsection 788 B (f), "Dental Schools", authorizes the funding of grants to partially offset the unreimbursed costs incurred by teaching programs providing oral health care to patients with AIDS. Such a "matching fund" would alleviate some of the financial burden faced by these treatment centers, allowing some centers to stay open despite chronic under-reimbursement.
AADS urges an appropriation of $5 million in FY 1990 to allow the initiation of this much needed program.

In addition to providing funding to reimburse the oral health care costs of treating AIDS patients, it is important that funds be provided to further educate dentists and other health care providers so that they will be trained to treat AIDS patients properly and without fear. Subsection 788 (B) (a-e) of the 1988 Health Professions Training Act recognizes health care providers training as the key to providing treatment and authorizes the funding of grants to assist schools and academic health science centers in meeting the costs of such projects. Unfortunately, last year Congress did not provide any funds for this program. We urge an appropriation of $10 million to implement this program for all health professions in FY 1991.

General Dentistry Residencies: General Dentistry programs provide dental graduates with the skills and clinical experience necessary to provide comprehensive care to a wide variety of patients requiring specialized or complex care, including the elderly, the medically compromised, and those infected with the AIDS virus. Dentists who have had the benefit of this advanced residency training are better prepared to provide comprehensive dental services, and rely less on specialists. Dentists who can serve a broad range of patient needs are in demand, especially in rural areas.

We reiterate our appreciation for this committee's efforts in securing an increased appropriation for General Dentistry training programs in the FY 1990 appropriations bill. This increased funding created approximately 58 new General Dentistry residency positions across the country. However, demand for this type of training continues to grow. The General Dentistry program is funded at slightly under $4 million, which is still inadequate to meet the need for these residencies. Fifty-five schools and over 500 hospitals and advanced dental education institutions must compete for General Dentistry funding. Many programs continue to be approved but remain unfunded, including those in states that are represented by members of this Subcommittee. Without Federal support, it would be extremely difficult to create new programs because of the lead time needed for these programs to become self sufficient and because of the high cost of dental equipment and instrumentation. To crver expansion of current programs as well as start-up funds for new programs, we urge the Subcommittee to appropriate $6 million for General Dentistry in FY 1991.

Geriatric Education Centers and Geriatric Training: Geriatric Education Centers (GECs) provide short-term faculty training, curriculum and other educational resource development, technical assistance and outreach. These programs are multi-disciplinary in nature, and are affiliated with other educational institutions, hospitals, nursing homes, community based centers for the aged, and/or Department of Veterans Affairs hospitals. Many of the GECs provide geriatric evaluation units that serve as centers for clinical training. In addition, health practitioners are provided continuing education, and health professions students rotate through GEC clinics.

In FY 1990, 33 GECs throughout the United States received $10 million; AADS recommends that the Geriatric Education Center program be funded at the FY 1991 authorized level of $13 million to continue existing centers and allow funding for additional GECs.

The Geriatric Training program provides for one- and two-year post doctoral fellowships for medical and dental faculty. In enacting this authority in 1987, Congress responded to the need for in-depth training of faculty in geriatrics. Recent evaluations of the adequacy and availability of health care personnel to meet the needs of elderly Americans through the year 2020 have revealed a shortage of adequately-trained faculty to train future health care providers in geriatrics. Previous funding supported the initial planning for the 23 Geriatric Training programs, including the development of curriculum, hiring faculty, and the first three months of fellowship training. However, last year a 25% reduction occurred in the Geriatric Training budgets when the second class of the two year program began training, but the funding that had been provided only covered stipend support for one class. Additional funds are necessary to cover stipend costs in FY 1991 as the Geriatric Training programs have become fully operational.

While the FY 1991 authorization level for this program is $13 million, AADS recognizes budget constraints and respectfully requests the provision of $7 million for Geriatric Training, which we believe would allow full funding of the Geriatric Training programs.

Disadvantaged Assistance: Programs available under the Disadvantaged Assistance authority are designed to recruit underrepresented minorities into health professions schools, to assist them in preparing to enter these schools, and to retain them once they are admitted. Health Career Opportunity Program (HCOP) institutional grants may be credited with keeping the percentages of Black and Hispanic students stable during the past several years. In addition, the Financial Assistance to Disadvantaged Health Professions Students program provides grants to needy medicine, osteopathy, and dentistry students that complement the HCOP institutional recruitment/retention efforts. The disparity between the number of minority students that have graduated from dental and other health profession schools and the number that would be required to achieve proportionate representation will grow unless adequate resources are available to address this problem. AADS recommends that the Disadvantaged Assistance program be funded at $28.8 million in FY 1991.

Exceptional Financial Need: Most health professions students must incur significant debt in order to complete their training. In 1989, the average dental student graduated owing $43,300. Many students are reluctant to incur such debt, but minority students from low-income families are especially fearful of borrowing thousands of dollars worth of student loans.

The Exceptional Financial Need (EFN) program provides scholarships for students with no financial resources so that they are not forced to assume high levels of debt in order to pursue a health professions career. AADS asks that a minimum of $10 million be provided for the EFN program in FY 1991.

Minority Health[1] - Programs not yet Authorized: Responding to the serious problems in the delivery of health care to our nation's disadvantaged minorities, Congress is considering new legislation that would authorize programs to expand recruitment of underrepresented minority students and faculty into health professions schools. The goal is to foster peer interaction and create role models so that students and faculty will be sensitized to the social and health needs of minority populations. AADS applauds the Administration's call for funds to address the problem of inadequate health care for minority citizens; however, we urge that this Committee not divert funds from other important health professions assistance programs to do so. Such a strategy that does not continue and increase support for existing federal assistance programs will only exacerbate the problem of health care delivery to Blacks, Hispanics, and Native Americans.

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[1] S. 1606 "The Disadvantaged Minority Health Act" was passed by the Senate November 20, 1989.

Health Education Assistance Loan: AADS is very concerned that the Health Education Assistance Loan program remain a viable "loan of last resort" for dental students. Students pay the market rate for these unsubsidized loans and are assessed an insurance fee to offset defaults. Twenty-five percent of all dental students borrow through the HEAL program to finance a portion of their dental education. Without HEAL loans, many students would be forced to discontinue their training.

The HEAL program costs, to date, have been borne entirely by participating borrowers. Last year, Congress provided $25 million as a supplement to the Student Loan Insurance Fund (SLIF), which repays lenders for defaulted HEAL loans, further strengthening the solvency of the SLIF. Yet, the Administration's proposed FY 1991 budget again recommends a phase down of the HEAL program. AADS believes that Congress cannot predict if an appropriation for the SLIF is needed unless an accurate forecast model is used to assess the solvency of the SLIF. However, DHHS's evaluation assumed termination of the HEAL program. Such an assessment assumes a shortfall in the SLIF since it does not account for revenues from new borrowers. AADS recommends that the Subcommittee obtain an evaluation from DHHS which assumes continued operation of the HEAL program in order to determine the sufficiency of the SLIF. AADS urges that Congress not restrict access to HEAL borrowing, and provide HEAL credit guarantees of up to $375 million. While low insurance premiums charged during the program's initial years created a shortfall in the SLIF, such a situation should not occur today when students pay an 8% insurance fee.

Research: AADS endorses the testimony of the American Association for Dental Research regarding priorities and funding of $201 million for the National Institute of Dental Research and of $110 million for the Agency for Health Care Policy and Research.

Within the NIH budget, AADS especially wants to note our concern about the Biomedical Research Support Grant (BRSG) program. The BRSG program is used to advance and strengthen the medical and health-related research programs of academic and scientific institutions by providing flexible funds for pilot research projects, central resources, support for new investigators, and interim funding for researchers who are awaiting funding of their research grants. AADS endorses the Ad Hoc Group for Biomedical Research Funding's recommendation to restore BRSG funding to its FY 1988 level of $58 million, and urges the Subcommittee to reject the Administration's drastic proposed cuts and modifications to this important program.

AADS also is concerned about the Academic Research Enhancement Award and National Research Service Award programs. We urge the Subcommittee to provide sufficient funding so that recruitment of scientists and training of individuals in specified shortage areas can be continued.

STATEMENT OF ELEANOR KOHN, VICE PRESIDENT FOR PUBLIC POLICY, NATIONAL MENTAL HEALTH ASSOCIATION

Senator ADAMS. Our next witness is Eleanor Kohn, vice president for public policy, the National Mental Health Association.

Welcome to the committee.

Ms. KOHN. Thank you for the opportunity. I come from Connecticut. I am a volunteer with Mental Health Association and I have come down here today to talk with you about programs that are going to have some major impact on the lives of people who suffer from mental illnesses.

But before I go into my official testimony, it occurred to me that prevention is the bottom line of everything that we do. And this committee is certainly going to be dealing with all kinds of tensions in the next couple of months, so I brought with me some copies of pamphlets on how to deal with stress, and how to decrease tension. We hope the committee can use them.

Senator ADAMS. Thank you very much. I am certain that we can and will.

Ms. KOHN. I suspect so. We are going to increase your tension by putting pressure on the committee to do what we think ought to be done. You already have our written testimony.

Senator ADAMS. Without objection, I will include it for the record.

Ms. KOHN. Thank you. I am going to take the time just to highlight just a few of the issues that we are extremely concerned about.

The first thing I would like to talk about is the proposed child and adolescent mental health research plan. We are asking that this committee allocate some $60 million to that plan. You know, kids in this country have gotten very short shrift from the mental health system. You heard from Dr. Pardes, and I will repeat that some 12 percent of the children of the country have a diagnosable mental illness; 7.5 million kids with a diagnosable mental illness. In some populations, that figure goes up to 20 percent.

And yet only one-fifth of them are receiving treatment that is adequate and appropriate. That is a terrible waste of kids' lives.

I would suspect that there would not be a person in this room who would turn away if they thought they had an opportunity, a fighting chance, to prevent suicide among young people; 2,000 kids a year—I am sorry, 5,000 kids a year commit suicide. The opportunity does exist to save some of those children, but without critical dollars, there is no reality to that opportunity. The $60 million could be used to provide answers to autism, to eating and conduct disorders, to childhood depression. Please, we ask you, do not turn away from this opportunity.

The second issue is that of the homeless. It is an issue that is high on our problem list but very low on our priority list. Do you find it as disconcerting as I do to think that this country can dig up $30 billion to put a platform in space and the President's budget is asking for one-third of the $100 million that was authorized for State grants to help the most abject of our population, the homeless people who are mentally ill? There is something wrong with those kinds of priorities.

We are urging you to support the full authorization of $100 million.

Finally, we share the committee's interest in better education programs around this country. But a prerequisite for children to learn is that they be emotionally and physically healthy. The seriously emotionally disabled kids need special attention in our school systems and they are not getting it. The dropout rate of those children is the highest of any group with handicaps. That number is going to increase, given the developmental disabilities that are being brought on by drug abuse, by prenatal and postnatal cocaine addiction.

We are asking for $15 million to go to a new Department of Education program which will enable States to develop programs dear to these children who have learning problems because of their emotional handicaps.

Incidentally, I think Washington would probably be in very good shape to get some of those grants because you already have your Education Department and your Department of Mental Health working close together on these programs—on these problems, rather.

PREPARED STATEMENT

I would just remind this committee, in closing, that children are our most endangered natural resource, and they certainly would be our best investment for the future.

Thank you.

[The statement follows:]

STATEMENT OF ELEANOR KOHN

Mr. Chairman, I am Eleanor Kohn, a volunteer with the National Mental Health Association (NMHA) and its Vice President for Public Policy. NMHA is a private, voluntary organization providing leadership across the entire range of mental health issues at local, state and national levels.

My testimony today concerns programs of the Alcohol, Drug Abuse and Mental Health Administration, which have tremendous impact upon the lives of persons who suffer from, or are at risk for, a mental disorder.

At the end of this testimony are our recommendations for support of these programs. We are recommending substantially higher spending than the President has requested. Once again, we are disturbed, as I am sure many members of this committee are, at the lack of priority for addressing the problems of mental illnesses. This, despite their devastating impact on our entire society.

At any one time, one in every five Americans suffers a mental disorder. Anxiety disorders, including panic and the phobias, which are frequently completely disabling, top the list followed by substance abuse, the affective illnesses including depression and manic disorders, and schizophrenic disorders. Obsessive-compulsive illnesses, also afflict untold numbers of people, making it impossible for them to lead normal and productive lives. The annual cost engendered by lost employment, reduced productivity, criminal activity, vehicular accidents, family dysfunction, related health care costs and social welfare costs for substance abuse and mental disorders bring the total cost to almost $250 billion. And dollar figures can, in no way, measure human suffering.

The Center for Disease Control has found that suicide is now the second leading cause of death, after car accidents, among young people aged 15-24. Five thousand young people kill themselves every year, nearly 500,000 other attempt it, and since 1950, the youth suicide rate has almost tripled. Suicides are also very prevalent at the other end of the age scale. The elderly have a suicide rate 1 1/2 times the rate for all ages.

These are poignant indicators of the urgent need to gain a better understanding of mental disorders, and to seek, far more vigorously, to bring appropriate and presently valuable treatments to those in need. Tragically, we continue to underfund mental health research and services. As scientific advances are made in the understanding of brain and behavior, our political system has not moved forward to adequately support the expansion of that knowledge and its translation into meaningful, accessible services for children and adults. We cannot allow that kind of neglect to continue.

Currently, fewer than one-fifth of those individuals with a diagnosable mental disorder receive mental health treatment from either mental health specialists or general medical physicians. New problems also loom on the horizon. Homeless families are a growing phenomenon. Teen-age pregnancy is epidemic. Child abuse is reported to be increasing. Violence is burgeoning. The number of children born of cocaine and other drug-addicted and AIDS infected parents is alarming. We must spend a dollar now on more research, better care and treatment, or we will pay for it later. Answers must be found to prevent and deal with these problems which are spawning ever more emotionally disabled populations. We are already facing the need to drastically increase services for affected children in mental health, health, education, social services, and possibly later in juvenile justice.

These costs to our society could be dramatically reduced, if we were willing to invest in such reductions. Unfortunately, as the Bush budget again so clearly demonstrates, our society appears to fear its enemies more than it loves its children. Given the choice between missiles, bank bailouts and children, children always lose. In the coming years, we will commit $3 billion each on plants to make nuclear weapons. Imagine what could be funded in health and education if just one of these were cancelled. Some federal departments have extraordinary resources available: The Department of Energy recently spent $1.4 million to print and send copies of its report on the supercollider by first class mail to people whether or not they requested it! Yet, we still lack the money to move vital research further forward into better understanding brain functioning and the misfunctions which cause the tragedy of mental disorders.

We strongly urge this committee to restore the cuts in the following ADAMHA programs, and to provide long overdue, and much needed increases in mental health spending.

High priority should be given to providing $60 million for the proposed Child and Adolescent Mental Health Research Plan, forwarded recently to Congress by the National Mental Health Advisory Council. Research into mental disorders of children and adolescents will lead to improved understanding treatment and potential prevention of childhood emotional, behavioral and mental disorders, including: Autism, Attention Deficit Disorders, The Depressive Illness, Conduct and Eating Disorders, Substance Abuse and addiction and others. Such an investment is certain to pay off.

Areas of research to be targeted would include:

1. Research to identify the best match between youngsters with a given disorder and specific treatments;
2. Expanded research on assessment, diagnosis and treatment and prevention and research concerning special populations, by increasing basic, behavioral, social science and neuroscience research;
3. Research to discover the risk and protective factors for young people in disadvantaged situations, particularly since the rates of substance abuse, homicide and suicide are escalating in this population; and
4. Service system research concerning effectiveness of services.

The National Institute of Mental Health (NIMH) Community Support Program and Child and Adolescent Service System Program (CASSP), both of which provide funds to states to improve systems for delivering care to adults and children who have serious disorders, need expansion. These programs have been found to be extremely effective, but for the last several years have lacked the necessary increases to even keep pace with inflation.

Prevention should also receive a high priority. NIMH initiated a small prevention demonstration program last year, targeted to preventing youth suicide and conduct disorders. We urge continuation of this program, with a small increase.

The NIMH Protection and Advocacy Program which provides advocacy services for people with mental illnesses, and investigates complaints of abuse and neglect in mental health facilities would be cut in half under the Bush budget. This program, which is overwhelmed right now with the demands being placed upon it by clients in crisis situations warrants additional support.

Expansion, not reduction, is needed in our efforts to train appropriately skilled professionals to work with increasingly difficult mental health problems, such as homelessness, babies born of addicted parents, abused children, etc.

Programs in ADAMHA and NIMH which address the needs of homeless persons need significant expansion. We have been calling for many years for $100 million (the amount first authorized by Congress) for grants to states to combat homelessness. Such a sum, spread around to help all states, could significantly spur on state and local governments to do more for homeless persons with serious mental illnesses.

The mental health portion of the ADM block grant has not only been shrinking steadily since 1980 compared with inflation, but last year was cut despite the increases appropriated for the substance abuse portion of that program.

In the Department of Education, there is also new authority in the Senate-passed bill, S 1824, for a new Part C discretionary grant program focused on the needs of children with serious emotional disturbance. These children have the highest drop out rate of any group of students with handicaps, and schools have tremendous difficulty in adequately meeting their needs. Our educational system is reeling under the effect of societal problems. Children whose minds and bodies have been mutilated by emotional and physical abuse and by illnesses over which they have no control find it hard to reap the benefits of improved educational programs. What is most tragic is the fact that early intervention can in many cases be highly effective. These new funds could be used to develop improved approaches and to coordinate mental health services with special education. We urge appropriation of $15 million for these purposes.

Program	FY 1990 Actual Spending	FY 1991 President's Request	FY 1991 NMHA Recommend.
NIMH			
Research	453.9	481.9	675.4
CSP & CASSP Service Demos. (Of which: Prevention)	28.1 (4.0)	26.9 (4.0)	41.0 (5.0)
Protection & Advocacy	14.0	8.0	24.0
Homeless Demos	6.0	6.0	6.0
Clinical Training	13.5	5.0	29.0
Al., Drug & MH Admin.			
Homeless State Grant	28.1	35.0	100.0
ADM Block Grant: Mental Health Portion	237.6	237.6	350.0

In conclusion, it is impossible to emphasize too strongly the critical need for increases in research into the causes of mental disorders, provision of services for those who are homeless or who have a mental disability, and investment in prevention and early intervention. The mental health field is explosive with promise. If we are not more thoughtful about our allocation of federal resources, this is a promise which will never be fulfilled.

Senator ADAMS. Thank you very much Ms. Kohn. My wife and I have recently spent considerable time visiting classrooms, not only examining the DARE programs but we have the problems of alcohol and drugs. And we have noticed that the most effective part seems to be that we have to push this clear down to the third- and fourth-grade level.

So my question to you is this. We have children with mental health problems and they are very much connected with alcohol and drugs, I am sure, throughout the entire United States. I can speak from experience for the counties that I have walked, big and small, big cities, and smaller towns, too.

How should we be addressing these mental health problems where the children are also involved with alcohol or drugs?

Ms. KOHN. I think one of the first things that needs to be done is we have to develop some kind of Federal leadership to develop an integrated and coordinate a kind of plan to deal with the problem. Efforts are going on now but we are attempting to deal with it in a very piecemeal fashion, and there has to be a central focus for pulling together the efforts of the alcohol people, the drug people, the mental health people. At the moment, children are falling between the cracks because each one of these service departments is saying the problem belongs someplace else.

I think we need to see some Federal leadership in finding a way of getting at the problem in an integrated fashion.

Senator ADAMS. Well, we would appreciate any further information you want to submit on it.

What I have seen is that we will have in some counties and some school districts and, of course, our State is similar to every other one. We have very many school districts, sometimes a number in one county, and you will see in one school district, an extraordinarily good program.

I mentioned the DARE program, where they actually are putting deputy sheriffs in talking to kids once or twice a week at fourth-grade level. And those kids have gone as they have gone into the middle school have an entirely different attitude and this is beginning to be reflected. But I can go to four school districts away, and nobody is doing anything like that.

So I guess what I am asking you is that you might give us some suggestions for a system of how the Federal Government becomes more effective with not just dealing with the States, but the countless school districts that we have.

Not that I see there has to be a uniform program, but at least one that is having some success should be able to easily communicate that to others and those who have a problem and have no program should not have to reinvent the wheel.

Ms. KOHN. I would suggest that the problem is not only within the Education Department. It is within the hospital situation, it is within the mental health system. And I do feel that its going to be necessary to bring together people from the justice system, from the health systems, from the mental health systems, from the education system, to develop this plan. And this can only be done at the Federal level.

Senator ADAMS. Thank you very much for your testimony. We appreciate it. And please leave the stress pamphlets.

Ms. KOHN. I shall be glad to.

Senator ADAMS. I shall read one tonight. If I have to listen to the floor like I did last night, I may read it twice.

Ms. KOHN. Thank you.

STATEMENT OF GERTRUDE AND IRVING SWERDLOW, EXECUTIVE STAFF, FAMILIES AGAINST CANCER, INC.

Senator ADAMS. Our next witnesses are Gertrude and Irving Swerdlow, Families Against Cancer, Inc.

We are pleased to have you with us this morning.

Mrs. SWERDLOW. Thank you Mr. Chairman. I wish to thank you and the committee for giving us the opportunity to appear before you today.

We are Dr. Irving and Gertrude Swerdlow, founders of FACT, Families Against Cancer. FACT is a coalition of cancer patients, their families and friends who want to see a new and more vigorous national policy on cancer. We speak for 70,000 petitioners who are angry and want to see their Government do more about cancer research. We will double and triple our numbers, and we will be heard.

Our presentation is divided in three parts. One, the cancer problem. A population the size of Denver, CO, died of cancer in the United States during 1989 alone. Cancer kills more children, youth, and adults to age 55 than any other disease. Each year, it kills 330,000 persons age 55 and over. It leaves behind a trail of grieving parents, siblings, children, and friends. It affected the four most recent families to occupy the White House.

Two, current status of cancer research. Our knowledge of cancer today approximates that available on polio 5 to 10 years prior to the development of a successful vaccine. Never before has there been a more opportune time to expand research on cancer.

As was described in our written statement to you, startling progress has been made in the unraveling of cancer metastasis. Further progress has been made in cancer treatment and early screening. Identifications of gene mutations and enzymes are momentous. These are the foundations for expanded cancer research.

Three, economics of cancer. The National Cancer Institute is not only this Nation's largest cancer center, but it is also the largest and most respected institute of its kind in the world. While we deplore Japan's global dominance in the production of computer chips and motor vehicles, we risk the NCI's world leadership on cancer. The President's proposed budget, adjusted for constant dollars by applying the scientific and medical indices, Mr. Chairman, not a CPI, provides less resources to the institute now than were appropriated 10 years ago.

About 4.5 million people died of cancer in the intervening decade. Earnings lost due to cancer exceed $65 billion annually and affect GNP and the gross taxable income base. Treatment of cancer exceeds $32 billion annually and contributes to national concerns for accelerating health care costs.

Medicaid and Medicare programs are stressed by the rising costs of cancer. Increasingly, medical insurance companies include in their health payments exemptions on payment for drugs and other treatments for cancer patients.

Alternatives to narrow the gap between the administrative and the bypass budget include:

Reduced tax expenditures.—The failed savings and loans are costing the taxpayers many billions of dollars in exhausted Federal insurance savings programs and in depreciated take-over assets. The appropriation process could divert $750 million of this bailout program to the national cancer program, with more lucrative results.

The Defense Department is likely to scrap $30 billion of inventories accumulated through its procurement program. On a per capita basis: $6 per annum to fight a deadly microscopic invader, cancer, annually, $1,300 to fight a potential foreign enemy.

Assess the peace dividend.—What better gift for the American people? For some years the Treasury has borrowed from the Social Security fund, at a relatively low rate of interest, to assist with its deficit financing. Earmark some of these moneys for cancer research, just as some of the NCI funds are currently earmarked for AIDS research.

Moneys invested for expanded cancer research will pay dividends in windows opened on new diseases.

The Congress, the President, and even local and State officials must be held accountable for the existing gap between cancer morbidity, cancer mortality and dollars appropriated by this Government through its trillion dollar budget.

PREPARED STATEMENT

Let your choice, Mr. Chairman and members of the committee, reflect the wishes of the people to endorse the NCI bypass budget.

Thank you, Mr. Chairman, for this opportunity to speak to you.

[The statement follows:]

STATEMENT OF IRVING AND GERTRUDE SWERDLOW

Mr. Chairman and Honorable Members of the Committee: Thank you for the opportunity to appear before you in support of the NCI ByPass Budget for fiscal year 1991. We are Irving and Gertrude Swerdlow, founders and executive staff of FACT: Families Against Cancer. FACT is a coalition of cancer patients, their families and their friends who want to see a new and more vigorous national policy on cancer. FACT is a not-for-profit organization located in Syracuse, New York. We speak for a constituency of 70,000 persons, an appreciable increase over the 13 individuals who initiated the organization a scant four years ago.

Our presentation is divided in three parts plus a conclusion: (1) The Cancer Problem; (2) The Current Status of Cancer Research; (3) An Economic Analysis of Cancer.

The Cancer Problem: A population the size of Denver, Colorado, died of cancer in the United States during 1989. A population the size of Cleveland, Ohio, is likely to die of cancer in 1990. Federal data inform us that a child born in the mid-80's has a 1 in 3 chance of coming down with cancer during a lifetime and that 50 percent of these will die of cancer. Cancer kills more children, youth and adults to age 55 than any other disease. It kills more than drugs, AIDS, and numerous other diseases combined. Each year it kills 350,000 persons age 55 and over. It leaves behind a trail of grieving parents, siblings, children and friends. Cancer does not discriminate by race or economic status. It affected the four most recent Presidential families to occupy the White House. It has struck members of Congress and their staff.

Current Status of Cancer Research: Our knowledge of cancer today approximates that available on polio 5 to 10 years prior to the development of a successful vaccine. Polio was a single disease which wreaked its havoc and has been terminated. Cancer, on the other hand, is comprised of dozens of related diseases usually characterized by tumor growth. It often recurs.

Never before has there been a more opportune time to expand research on cancer. For example:

1. Significant progress has been made in the unraveling of cancer metastasis. Failure to successfully control the metastatic process reaps more cancer deaths than those resulting from the original tumor. Scientists at the

NCI Pathology Laboratory have identified three types of protein that enable metastatic cells to penetrate blood vessels, exit them, and eventually attach to a second tumor site.

2. More recently, scientists at the same laboratory have purified a human protein inhibitor, TIMP-2, that can inhibit Collagenase IV, an enzyme characteristic of cancer cells and which degrades connective tissue. Collagenase IV is closely associated with tumor invasion and with metastasis.

3. Researchers have found a family of inhibitors to the enzymes produced by the cancer cells and are developing an understanding of specificities of the inhibitors to these enzymes. Basic research has paved the way for impending clinical research on these inhibitors.

4. NCI scientists have identified NM 23, a unique protein which may be lost or reduced when cancer cells undergo the metastatic process. Better understanding of NM 23 may identify those patients with higher levels of the protein and who do not require painful and costly longer term cancer treatments.

5. Tumor-infiltrating lymphocytes (TIL) derived from human cancers and grown in the laboratory, may become a means of attacking the cancerous tumors. TIL, gene insertion, may also become therapeutically applicable to a number of other diseases.

6. Current research on chronic myelogenous leukemia has revealed that the disease is triggered by the fusion of two parts from two broken chromosomes: gene ABL from chromosome 9 and gene BCR from chromosome 22. The resulting hybrid gene produces protein P210, a protein which changes healthy cells into cancer cells. By transferring the leukemia cells to healthy mice, scientists hope to achieve the means to block the action of the P210 protein and consequently prevent the disease. Patients with chronic myelogenous leukemia have a survival rate of only 1 in 6, and even then survival is likely to be short term. Exposure to high levels of radiation may be the cause for the chromosomes to break.

Economics of Cancer:

1. The National Cancer Institute is not only this nation's largest cancer center, but it is also the largest and most respected institute of its kind in the world. While we deplore Japan's global dominance in the

production of computer chips and motor vehicles, we risk the NCI's world leadership on cancer. The President's proposed budget, adjusted for constant dollars by applying a scientific and medical indice, provides less resources to the Institute now than were appropriated 10 years ago. About 4-1/2 million people died of cancer in the intervening decade.

2. Senior scientists have departed the NCI in critical numbers in response to more competitive offers from academia and the private sector.

3. Earnings lost due to cancer exceed $65 billion annually and affect GNP and the gross taxable income base.

4. Treatment of cancer exceeds $32 billion annually and contributes to national concerns for accelerating health care costs.

5. Increasingly medical insurance companies include exemptions for payments of drugs and other treatments for cancer patients in their health policies.

6. Medicaide and Medicare programs are stressed by the rising costs of cancer care.

7. Job discrimination that includes job loss, denial of employer's health insurance, and restraint of job promotion has plagued cancer patients. As recently as 1987, a bill that proposed to outlaw discrimination of the cancer patient or former cancer patient could not get through the Congress.

8. Alternatives to narrow the gap between the administrative and the ByPass Budget include:

   a. Reduce tax expenditures, especially where corporations pay 7 percent or less of their net income in corporate taxes.

   b. The failed Savings and Loan Banks are costing the taxpayers many billions of dollars in exhausted federal insurance savings programs and in depreciated takeover assets. The appropriation process could divert three-quarters of a billion dollars of this bailout program to the national cancer program with more lucrative results.

   c. The Defense Department is likely to scrap $30 billion of inventories accumulated through its procurement program. A viral microscopic invader, cancer, is also deadly and must be defeated. On a per capita basis, $6 per annum to fight cancer; $1300 to fight a foreign enemy.

d. Assess the Peace Dividend. What better gift for the American people if part of the Dividend goes to fight cancer! For those who propose applying it to shorten the budget's deficit, let us say that reducing cancer care and lost tax base are also deficit reducing.

e. For some years the Treasury has borrowed from the Social Security Fund at a relatively low rate of interest to assist with its deficit financing. Earmark some of these monies for cancer research just as some of the NCI funds are currently earmarked for AIDS research.

f. Monies invested for expanded cancer research will pay dividends in windows opened on new diseases.

Conclusion: Before you, Mr. Chairman, and members of the Committee, are petitions representing 70,000 people from among 45 states. Some of these people are your own constituents. They know, well, that cancer does not stop at a state's borders. They know, too, that cancer is a national problem that demands a national solution. These petitions make the needs and desires of these people known to you. They are willing to march. Are we heard?

Choice between scarce resources and unlimited wants will make your appropriations decisions more difficult. Remember the NCI is in a double bind: Its budget is restricted by the total NIH appropriation and the NIH appropriation is decided within the limits set by the discretionary budget.

You know that there is no magic bullet to overcome cancer. Fortunately for our children and grandchildren, scientific breakthroughs are now so significant that the challenge to you is to expand the research effort. New ideas must be explored; laboratory space must be adequate; medical technologies must be applied and our human capital assets put to good use. Inefficient cancer centers should be upgraded and new ones opened in appropriate areas where none are now operative. The NCI, for its part, should keep the public better informed of its achievements and promote support services for cancer patients and their families through these centers.

The Congress, the President and even local and state officials must be held accountable for the existing gap between cancer morbidity, cancer motality and dollars appropriated by this government through its trillion dollar budget. Let your choice, Mr. Chairman, reflect the wishes of the people. Otherwise, the cancer carnage will take another 5-1/2 million lives before the end of this century.

Thank you, Mr. Chairman, for this opportunity to speak before your Committee.

Senator ADAMS. I want to thank both of you for your testimony; it was excellent. And I have no further questions because you have covered it very well, and I have asked my prior questions on the amounts of money, which I understand you support. Thank you very much.

Mrs. SWERDLOW. Mr. Chairman, we would like our entire statement submitted for the record, please.

Senator ADAMS. Without objection, your entire statement will appear in the record as though given. Thank you both.

STATEMENT OF JOHN CALHOUN

Mr. John Calhoun has been required to leave for another meeting. Without objection, his statement will appear in the record in full as presented to the committee.

[The statement follows:]

STATEMENT OF JOHN A. CALHOUN, EXECUTIVE DIRECTOR, NATIONAL CRIME PREVENTION COUNCIL

Mr. Chairman, Members of the Committee:

I am John A. Calhoun, Executive Director of the National Crime Prevention Council (NCPC). Before coming to NCPC I served as the Commissioner of Youth Services in Massachusetts and subsequently as United States Commissioner of the Administration for Children, Youth, and Families (ACYF) at HHS. I'm here to encourage your subcommittee to fully fund ADAMAHA's office of Substance Abuse Prevention in FY'91.

NCPC's philosophy of crime prevention is two-fold: It includes protection and safety in addition to community building.

Crime creates two victims: the victim seen -- a person injured, property taken, graffiti on public buildings. The other victim, unseen, is the community -- civic lifeblood drying up, people not interacting with each other, saying, "I don't go out after 4:00 p.m. anymore..." --- "I won't walk in the park...". This is exacerbated by crack which paralyzes communities, closing sidewalks to kids, parks to strollers, stoops to those who would simply visit. Crack, the narcotic license which allows one to kill for a jacket or maim for a slight; crack which can sunder the most elemental of bonds -- that between mother and child.

Our strategies must prevent harm to both victims -- crime against individuals and against the community fabric. Safety is important. Safety for its own sake is dangerous. The purpose of safety must be to create a context in which the bonds which bind us together as a human family can develop.

The Council is an effective public-private partnership receiving the bulk of its public funding through the U.S. Department of Justice's Office of Justice Programs and private grants from individuals, foundations and corporations. Our work ranges from the award-winning public service advertising featuring McGruff to production of materials to demonstration programs involving youth, schools and communities.

Because we are passionate believers in creating partnerships, we have joined with OSAP to produce and distribute a McGruff comic and coloring book. NCPC and OSAP have teamed on an important new initiative to reach young children before they face a decision about using drugs. OSAP, through its youth review team, identified the need for colorful and entertaining material able to reach young children. Because McGruff the Crime Dog is recognized by 99% of all children ages 6-12, and because each comic book reaches four or more individuals and are read at least seven times, OSAP and the Council created the McGruff Surprise Party comic book. The book was focus-group tested with children in the 3rd and 4th grades to ensure that the message and the medium would work. To reach children in primary grades OSAP printed 2 million Crack Down on Drugs coloring books. Copies of these materials have been included as part of my written testimony.

In addition to working with OSAP on drug abuse prevention with young children, we are working with local community groups to test and implement effective strategies to reduce drug abuse, crime and fear. Through a 1989 grant from the Justice Department, NCPC created the Community Responses to Drug Abuse Program. We chose eight test sites, (one in your home state of Iowa), where community groups worked on well-defined short and long-term goals to combat drug abuse. The learnings to date have been thrilling: we have seen local groups to learn to close crack houses, use noise abatement laws, nuisance laws, hold parades and vigils, start mentoring programs for teens, and work more closely with law enforcement to reduce drug abuse and rebuild community strength. In some sites, including Des Moines, Waterloo and Council Bluffs, Iowa, significant drug abuse prevention accomplishments have been achieved. I've included a status report on this important program and a paper on community building along with my written testimony.

I applaud OSAP's emphasis on increased awareness through its clearinghouse function and its public service advertising -- simply getting the word out. Second, OSAP is to be commended for seeking ways to apply what it has learned through such strategies as the community partnerships initiative (how institutions can work together; stimulating ways individuals can work together) --- in essence, attempting to shift the community ethos, which will eventually make treatment less and less necessary. OSAP has also focused attention on drug abuse prevention in high-risk populations -- at-risk youth, pregnant teens -- and strategies for community mobilization.

I'm here to back your support of OSAP's work in the areas of community building and drug abuse prevention for children. In FY'90 your Committee funded a new community-based drug prevention program through OSAP. Our learnings with Justice Department funds demonstrate that this is money well-spent. I urge you to continue funding this program in FY'91 and beyond. You have my assurance that we will work closely with OSAP and the Justice Department to ensure coordination of efforts on community-based drug prevention programs. NCPC and OSAP share a commitment to implementing sound and workable long-term prevention programs. I urge your Committee to fully fund the Administration's request for $101 million for OSAP community programs in FY'91.

I would be pleased to answer any questions and thank you again for the opportunity to testify.

STATEMENT OF SAMUEL L. KATZ, CHAIRMAN, DEPARTMENT OF PEDIATRICS, DUKE UNIVERSITY MEDICAL CENTER, ON BEHALF OF THE INFECTIOUS DISEASES SOCIETY OF AMERICA

Senator ADAMS. Our next witness will be Dr. Samuel Katz of the Infectious Diseases Society of America.

Dr. Katz, welcome to the committee.

Dr. KATZ. Thank you very much Senator Adams. Because of time constraints, we have also submitted a complete set of remarks, which we hope will be on file with the committee.

Senator ADAMS. Without objection, the entire statement will be submitted for the record as though given.

Dr. KATZ. Thank you. In the allotted few moments we have I would like to speak on behalf of the budget for the National Institute of Allergy and Infectious Diseases. Representative Keys already alluded to some of the exciting research and immunology which goes on in that institute which had bearing on her interest in multiple sclerosis.

Our society, which represents more than 2,000 members who are engaged in infectious disease research and in infectious disease practice, are concerned about the current rate of awards for approved grants. The practice of so-called downward negotiation for grants that are awarded and then lose 14 or more percent of their funding.

The flat line increase for training grants. We are concerned about the flat levels of proposed funding for programs designed to combat sexually transmitted diseases. In your own constituency, Drs. Larry Cowie and King Holmes at the University of Washington have been national leaders in this field, and I am sure you are aware of the type research that has been so productive and yet needs so much more to be done.

Over the coming years, we would ask that the award rate be raised to 50 percent of competing research projects and grants. Currently, we will be fortunate if 24 percent are funded, given the current budget and the projections. Infectious disease research is among the most cost beneficial that is conducted by the National Institutes of Health. I do not think I need to remind you of the figures. In 1965 we lost 25,000 babies due to congenital rubella. Last year, there were only two reported in the entire United States. We used to have 25,000 cases of polio every year in the United States. We have less than 10 a year now. I could go on and talk about measles, tetanus, diphtheria, but I will not bore you with that. Only to remind you that research funding for the National Institute of Allergy and Infectious Diseases is translated into better health care and preventive medicine for all our citizens.

Another aspect of the administration's budget provides no increase in the number of research centers, nor any increase for career and minority biomedical research support grants. In fact, they will be diminished by as many as 11 in the coming year if there is no change in the funding.

The flat line increase for training grants is unacceptable, given our national concern for the preparation of a new generation of biomedical researchers and physician scientists. We need funds to conduct studies of pertussis vaccine, a leading area in the whole field of immunization and one which needs to be resolved to restore our citizenry's confidence in our immunization programs.

Last year, the Federal committees as well as professional societies recommended doses of measles vaccine for children throughout the country. There has been no funding provided. In fact, the Centers for Disease Control budget for immunization has been diminished over the coming year, and yet we are having outbreaks of measles in Los Angeles and Chicago, in New York, in Houston, in Miami, and many other cities.

We believe that only through an increase in appropriations substantially above the President's request can the National Institute of Allergy and Infectious Diseases meet its stated goals.

This is the lead institute in research for control of AIDS. The advances that have been made since the discovery of the virus less than 5 years ago are incredibly impressive and are due to the exceedingly fine support that this committee has given to NIAID in the past.

We ask you to look with great care at the budget for the coming year. Thank you Senator Adams.

Senator ADAMS. Thank you very much Doctor.

You are requesting a total of $9 million for the study of pertussis vaccines. What do you estimate an effective vaccine would save in terms of years, work productivity, or health care costs?

Dr. KATZ. I cannot give you a dollar figure but I can tell you of the cases of pertussis that are occurring in the United States today, 26 percent result in hospitalization. Of those, 25 percent of that 26 percent or one-fifth, end up in intensive care units, where they are hospitalized at costs of several thousand dollars a day. The chronicity of the illness that results is such that you have children who are left as pulmonary cripples.

I cannot give you a total dollar figure but I think those give you some insights into what it must be.

PREPARED STATEMENT

Senator ADAMS. Thank you very much doctor, and thank you for your testimony.

Dr. KATZ. Thank you Senator.

[The statement follows:]

STATEMENT OF SAMUEL L. KATZ

The Infectious Diseases Society of America ("the Society") is pleased to present its views to the Senate Appropriations Subcommittee on Labor-HHS-Education in regard to funding for the National Institute of Allergy and Infectious Diseases ("NIAID"). The Society is particularly concerned with the current rate of awards for approved grants, the practice of so-called "downward negotiation" for grant funding, and the flat line "increase" for training grants. We are also concerned with the flat levels of proposed funding for programs designed to combat sexually transmitted disease. In addition, we ask the Committee to carefully review additional opportunities to fund studies on the safety and effectiveness of new acellular pertussis vaccines.

Infectious Disease Specialists

The discipline of infectious diseases is a subspecialty of internal medicine and will soon become a subspecialty of pediatrics. Infectious disease specialists focus on the interaction of the patient's immune system and the various organisms (viruses, bacteria, fungi etc.) which cause infections. The immune system is critical to the healthy functioning of the human body because it provides the necessary protection against these external invaders, as well as against certain types of cancers. Without an immune system, humans could not survive.

The Society is comprised of approximately 2,500 specialists in the field of infectious diseases, including physicians involved in clinical and basic research, as well as physicians who concentrate on clinical practice. Infectious disease specialists are the primary care physicians for patients suffering from AIDS, which attacks the entire body, not just a specific organ.

Increased Award Rate for Approved Grants

The Society recommends appropriations sufficient to allow an award rate of 50 percent for competing research project grants. The funding of additional competing investigator initiated research projects will allow NIAID to capitalize on the exceptional basic research advances made in the last decade and develop them to the point where clinical application will become a reality. Only 24 percent of approved grants would be funded under the proposed budget for NIAID, an inadequate level to sustain the progress made thus far.

Among the NIH colleagues, infectious disease researchers are in the unique position of being able *to eliminate* some diseases, such as smallpox, polio, diphtheria, pertussis, and rubella, through the use of vaccines and antibiotics. Other disciplines must rely solely on education efforts to prevent disease occurrence and then only treat patients to minimize the effects of the disease. Recently, infectious disease researchers have been able to predict with some certainty the year-to-year changes in the influenza virus and design a protective flu vaccine. Elimination of disease has tremendous potential for cost savings in terms of life years and work productivity, in addition to the obvious savings in health care costs.

Therefore, an enhanced award rate of 50 percent to fund 1,300 competing grants versus the proposed 24 percent/580 grants represents a significant and effective investment in the nation's health.

Full Funding for Grant Awards

Currently, grants awarded at NIAID are automatically cut 14 percent from the budget level recommended by study sections. These so-called "downward negotiations" allow greater numbers of grants to be funded, but at lower levels. This practice has been demonstrated to greatly hinder researchers who must maintain prescribed personnel levels, but are subsequently forced to allocate less money for needed equipment and supplies. By the time expert reviewers recommend funding for a research grant, the recommended level is often scaled down from the requested level. The automatic 14 percent downward negotiation for every competing and non-competing grant is most damaging to this research.

Based on the proposed 1991 appropriation levels for grant awards, reductions in grant levels would continue at a rate of 10 to 14 percent. In the judgment of the Society, appropriations for grant awards must be designed to assure ***full funding*** of those awards if our nation is to fully reap the vast benefits of these meritorious research efforts.

Increased Levels for Training and Research

The Administration's budget provides no increase in the number of research centers or funds, nor any increase for career and Minority Biomedical Research Support ("MBRS") grants. In the Society's judgment, an additional $5.1 million is needed to increase the number of AIDS research centers from 12 to 18, expand a new program for tropical diseases research, and enable full funding of asthma research centers and centers for immunologic research. These research centers programs are important because they integrate basic and clinical research to facilitate the transfer of technology to primary care providers, as well as provide a stable environment to recruit and train physician-scientists, a great challenge in itself. Most importantly, the research centers are central to the rapid dissemination of research findings to the scientific and lay communities.

An additional $5.4 million would fund career and MBRS research grants, 50 percent more than that requested by the President, which reflects no increase from 1990. In fact, since 1988, the number of actual research grants for career and MBRS research has ***declined*** by 11. The professional judgment increase would fund 46 more career awards and more than double funding for Minority Biomedical Research Support.

Given the concerns of NIH, and national concerns that the number of well-trained biomedical researchers, particularly physician-scientists, is unacceptably low, the flat-line increase for training grants is unacceptable. The level of support for training should be double the level requested by the President, for a total of almost $35 million for individual and institutional grants.

Attracting and retaining mid-career scientists and top new graduates has been the focus of recent Congressional hearings and legislation. The Society supports expansion of the loan repayment plan now utilized for AIDS research programs, whereby researchers whose debt is more than 20 percent of their salaries can receive up to $20,000 per year for three years toward their loans if they stay in the AIDS program. If NIAID is going to compete effectively with private practice and corporate research programs for stellar talent, this highly effective program should be expanded.

Study of Pertussis Vaccines

Mr. Chairman, we also ask that the Committee pay close attention to the inadequacy of the Administration's budget for the evaluation of potentially safer pertussis vaccines. As we understand it, the budget includes $3.5 million for one study that would compare the efficacy of one of eleven acellular vaccines with the existing whole cell vaccine, as well as with a placebo. Because several of the acellular vaccines hold great promise, another clinical trial involving at least one additional acellular vaccine could prove necessary during fiscal year 1991, and thus the Society recommends an additional $3.5 million appropriation for this purpose. In addition, it is likely that NIAID will be asked to assist in funding a safety trial in the United Kingdom comparing the existing whole cell vaccine to one or more acellular vaccines. This study would presumably resolve the issue of the extent of neurological damage, if any, presented by either type of vaccine. An additional appropriation of $2 million to reflect the potential of NIAID contributing to this trial is in the Society's judgment, desirable.

Centers for Disease Control

Mr. Chairman, the Society has great concern over the proposed budget for the Centers for Disease Control ("CDC"). As you know, the CDC is charged with increasingly important responsibilities to protect the public health, including immunization programs and programs to combat sexually transmitted diseases. The CDC has recommended that children routinely receive a second dose of measles vaccine, yet the President's budget does not propose sufficient funds for CDC to purchase the second vaccine on behalf of states and localities. The budget proposes no increase for programs designed to prevent sexually transmitted diseases, despite the fact that the incidence of these diseases has escalated enormously in recent years. We understand that over the next few days, the CDC Coalition will formulate a proposed CDC budget for your consideration. The Society is a member of the Coalition and wishes to bring to your attention its alarm over the budget proposal for virtually no increase in funding for the important mission of the CDC.

Concluding Recommendations

The Infectious Diseases Society of America believes that only through an increase in appropriations substantially above the President's request can NIAID meet its stated goals for advances in research and training for infectious diseases, including AIDS. Particularly in need of this Committee's attention are greater and more complete funding of grant awards and adequate increases in trainees and research centers. The Congress must take positive actions to ensure that NIH remains a desirable environment in which to study, and worthy of the goals of our nation's best and brightest scientific minds.

The infectious diseases community appreciates the consideration by the Senate Appropriations Subcommittee on Labor-HHS of its recommendations and past support for NIH activities.

STATEMENT OF JOHN F. O'DONNELL, DIRECTOR OF LEGISLATIVE POLICY, AMERICAN DENTAL ASSOCIATION

Senator ADAMS. Our next witness is Mr. John F. O'Donnell, American Dental Association.

Welcome, Mr. O'Donnell.

Mr. O'DONNELL. Thank you Senator. On behalf of the American Dental Association, I want to thank you for the opportunity to testify today. You have our statement. We ask that it be included in the record.

Senator ADAMS. Without objection, the entire statement will appear in the record as though given.

Mr. O'DONNELL. In the time allotted, I just want to emphasize this. The initiatives in dental research, dental education, and public health that we ask you to support in our statement are of particular benefit to those in our society who most need help: people with chronic diseases, developmental disorders, life-threatening illnesses—some of these quite rare, others all too common, but even for the rarest of those diseases, rarity is small consolation to someone who is suffering~~ from it; th~~e elderly, the fastest expanding segment of society; and the people with the most severe oral health problems, those in the inner cities and remote rural areas whose access to dental care is most limited, and the economically disadvantaged.

Without the continued financial support from the Congress, dental education, which is, I am sure is an extraordinarily expensive proposition, is simply not possible for talented students from low-income families. And without dentists representative of all strata of our society, our current access problems will simply continue indefinitely.

PREPARED STATEMENT

Those in communities without fluoridated water supplies, communities that want to fluoridate but are not in a financial position to do it, full funding of the preventive health block grants programs provides these communities a reasonable chance to obtain the necessary financial support within their respective States.

That is all I wanted to say, I wanted to emphasize, so I will not take any more of your time. If you have any questions, I would be happy to try to answer them.

[The statement follows:]

STATEMENT OF JOHN F. O'DONNELL

Mr. Chairman and Members of the Subcommittee:

I am John F. O'Donnell, director of legislative policy for the American Dental Association.

The Association thanks you for this opportunity to testify in support of federal funding for research, education and disease prevention. These initiatives are essential to the dental and general health of our nation, and they are all contingent upon continued appropriate federal support.

Dental Research

In the last decade of this century, the National Institute of Dental Research is prepared to pursue two major initiatives: Research addressing the needs of special care patients, and the Research and Action Program for Improving Oral Health of Adults and Older Americans.

The first initiative seeks answers for people afflicted with systemic diseases that adversely affect their oral health: diabetes, cystic fibrosis, lupus and AIDS, as well as rarer diseases, such as scleroderma, in which the mouth opening is limited from hardening and shrinkage of skin and connective tissue; osteogènesis and dentinogenisis imperfecta, in which bones and teeth are subject to fracture because of poor development; ectodermal dysplasias, developmental failure of essential components of skin and teeth, and Sjogren's syndrome, a condition of dry eyes and dry mouth, often complicated by arthritis.

Also included as special care patients are persons suffering from systemic treatments. Among these are patients who suffer oral complications as the result of chemotherapy or radiation treatment involving the head and neck. Oral cancers, chronic facial pain conditions and taste and smell disorders are also addressed by this research initiative.

Specifically with reference to AIDS research, we note the intention of NIDR to expand earlier studies into the role of saliva as a transmission agent of HIV. Results to date indicate that saliva probably does not transmit HIV and, indeed, may be an inhibiting factor in such transmission. In addition, through collaboration with the Walter Reed Army Institute of Research, NIDR is exploring new treatments for oral conditions in HIV-infected persons and expanded study of the severe periodontal disease found in some of these patients.

AIDS symptoms often first manifest themselves in the mouth. Thus, the dentist is often the practitioner who introduces afflicted persons into the health care system. NIDR is convinced that this primary point-of-entry role for dentists will expand in the future.

The second initiative, the Research and Action Program for Improving the Oral Health of Adults and Older Americans, pursues the elimination of toothlessness in future generations of Americans and the prevention of further deterioration of oral health of individuals with already compromised detention.

In 1988, the Congress urged NIDR to undertake a specific initiative to "improve the oral health status of the current seniors and to ensure that future generations of older Americans never again experience the oral health problems of past generations." The recommended target for the Institute was the elimination of edentulousness in the United States. To help initiate this long-term effort to improve the oral health of older Americans, modest funds were added to the FY 1988 appropriation.

NIDR has responded to Congressional intent by making the Research and Action Program one of its highest priorities. Both basic and clinical research are being pursued on normal age-related changes in the oral tissues, as well as changes due to oral or systemic disease and treatments. "Action research" will involve NIDR in the transfer of laboratory findings to public and professional use through clinical trials, demonstration research, and similar efforts. The Institute is placing special emphasis on identifying individuals, of any age, who are at risk for oral health problems for any reason. The program, then, complements the special care initiative by adding to medical and dental risk factors demographic factors, such as age, education, income, race and ethnicity -- factors which past studies have shown significantly influence oral health status.

To support NIDR in these research initiatives, the Association recommends appropriations of $210 million.

Dental Education

In education, perhaps the most significant programs for addressing the needs of special care populations, and elderly persons, are the General Practice Residency, the Geriatric Training and the Geriatric Education Centers programs. These programs are critical to the training of faculty and development of curriculum that, in turn, will produce practitioners with the special clinical and management skills to treat these special patients.

To advance these programs in 1991, the Association urges the appropriation of $26 million ($6 million for the General Dentistry Program, $13 million for Geriatric Education Centers, and $7 million for Geriatric Training.)

The cost today of a dental education -- and the resultant debt levels of graduating dentists -- are creating substantial disincentives to seeking a dental education. Such disincentives, of course, most severely affect students from economically disadvantaged backgrounds, disproportionately minority students, who are already underrepresented in the national dental student body.

Continued Congressional support for Disadvantaged Assistance programs -- the Health Career Opportunity Program and the Financial Assistance to Disadvantaged Health Professions Students Program -- is essential to recruiting and retaining black and Hispanic students in health professional schools, and providing grants to students in extreme financial need.

For FY 1991, the Association recommends that programs under the Disadvantaged Assistance authority be funded at $28.8 million.

The Exceptional Financial Need (EFN) scholarship program is another critical element of the effort to maintain and increase professional school enrollments of talented minority students from low-income families. This is especially true for dental schools, where the four-year cost, exclusive of normal living expenses, now averages nearly $50,000.

The Association recommends that the EFN program be funded at no less than $10 million for FY 1991.

Further, the Association recommends that Congress begin funding training in dental and other professional schools and academic centers directed toward the treatment of AIDS patients. We urge that $10 million be appropriated in FY 1991 for this purpose.

Disease Prevention

The Dental Disease Prevention Activity within the Centers for Disease Control has demonstrated its capability to provide oral health promotion and disease prevention services to the public. To continue its work, and to advance its Adult Oral Health Initiative and Oral Cancer Prevention Initiative, appropriations of $5.5 million are requested for FY 1991.

Finally, the Association recommends strongly funding of $89,716,000 for the Preventive Health Block Grants program, so that essential public health initiatives may continue. This is particularly important with respect to expanding opportunities for communities to fluoridate their water supplies, thus joining the Nation's 7,700 communities now reaping the benefits of this tremendously effective oral health measure.

Thank you for your attention.

Senator **Adams**. On page 6, you have mentioned the fluoride program.

Mr. O'**Donnell**. Yes, sir.

Senator **Adams**. I had an uncle who was a dentist who was unfortunately one of those who opposed this. I used to have terrible arguments with him. There is new information coming out. Can you give me any statement on fluoride toxicity. Indeed, I have always supported it, but could you comment on this new information about, I do not know whether it is good, bad or indifferent, that says that fluorides tend to be toxic? Well, I know they are toxic, I mean in the way they are used.

Mr. O'**Donnell**. Being neither a dentist, a scientist, nor educator, I cannot give you a scientific response. I can tell you this, that the information that has appeared in the press is drawn from raw data, released by the researchers. It is being analyzed now and, of course, will be looked at very carefully.

At the same time, I think everybody has to understand that the other studies, the many other studies, regarding the effect of fluoridated water supplies upon the populations that live in those communities, and perhaps most convincingly, I think, the empirical information from people who have lived most of their lives, many all of their lives, in either naturally fluoridated or artificially fluoridated communities just simply does not bear out any difference in the incidents of in this case, what you mention, cancer.

So, you know, certainly there is a study that provides any information in regard to a public health measure, it has to be looked at very carefully, and it will be looked at very carefully. But we see no reason to believe that there is any less safe——

Senator **Adams**. We will not worry about changing position at the moment. We will await further information.

Thank you very much Mr. O'Donnell for your testimony this morning.

Our next witness is Alan Brownstein, executive director of the National Hemophilia Foundation. Is he here or has he already left the room?

[No response.]

STATEMENT OF RAYMOND D. FOWLER, CHIEF EXECUTIVE OFFICER, AMERICAN PSYCHOLOGICAL ASSOCIATION

Senator **Adams**. All right, our next testimony is from Dr. Raymond Fowler of the American Psychological Association.

Welcome Dr. Fowler.

Dr. **Fowler**. Thank you, Senator Adams. Mr. Chairman, thank you for this opportunity to testify on behalf of the American Psychological Association. The APA has 70,000 members—researchers, educators, and clinicians—and 30,000 students and other affiliates.

Research is basic to psychology and it is on that subject that I want to address you briefly today.

I will touch on three topics in this statement. The first, the need for additional funding for NIH and for the Alcohol, Drug Abuse, and Mental Health Administration, both for non-AIDS and AIDS research. The second is the critical role the Federal Government plays in encouraging young people to pursue careers in science.

The third, is the vital need for increased behavioral research to improve the Nation's health.

The NIH budget has not seen much growth in recent years. The administration's proposed increase for fiscal year 1991 would not allow NIH to support fully its current level of funding, falling nearly $400 million short of NIH estimated current services. Decreasing numbers of new grants in most NIH programs and downward negotiation of current grants are problems in nearly all institutes.

As strong and consistent advocates of AIDS research, we feel well qualified to urge that non-AIDS research dollars be increased, not sacrificed, to pay for the vital needs of AIDS funding expansions.

As one of the cochair organizations of NORA, the National Organizations Responding to AIDS, APA strongly endorses the $2.9 billion funding recommendation for AIDS and particularly the $764 million proposal for prevention activities at the Centers for Disease Control and ADAMHA.

At ADAMHA, the proposed number of new and competing grants is reduced by almost 31 percent from fiscal year 1990. Like NIH, ADAMHA will average 20 percent award rate for new grants, down from 33 percent this fiscal year. So only one in five peer review-approved research projects can be funded.

We urge your support at funding levels that will sustain the progress in these research institutes and that will continue to yield solutions to many of our gravest national problems. APA recommends a total ADAMHA appropriation of $1.197 billion and a total NIH appropriation of $9.2 billion.

The issue of research training and clinical training is vitally important to the scientists at APA. Because the odds against obtaining funding at current appropriations level are so great, there is very real fear in the scientific community that young researchers will be unable to compete and will turn into other careers.

Last fall, APA commissioned a Rand Corp. study, and our report on that indicated that there had been a striking decrease in the proportion of awards to researchers under the age of 35. Not only is excellent peer-reviewed research going unfunded, but potentially brilliant scientific careers lie fallow.

Mr. Chairman, there is some indication from surveys that almost one-half of the members of the academic community will retire within the next 15 years. These established, well established academic scientists, are the ones who are receiving the grants, and rightfully they should. They are the experienced scientists.

But almost none of the new generation who have to take their place are receiving grant funding any more, and who will take the place of our established scientists when they go into retirement in the very, very near future?

One action by the Federal Government which could help keep young scientists in research is an expansion of the research and clinical training programs at NIH and ADAMHA.

I will close by emphasizing a promising area of behavioral research that deserves additional support by the Federal Government. Health and behavioral research is the study of how human behaviors can affect human health and how to influence people to do what is good for them and stop doing what is bad for them. This subcommittee has directed several times that NIH increase the percentage of health and behavioral research, which has hit a plateau of around 3 percent of research expenditures.

The Institute of Medicine's report, "Health and Behavior," a research agenda, cosponsored by NIH, identified lifestyle and behavioral factors as the major causes of death in the United States, and we spend only 3 percent of our budget in dealing with those major causes.

Similarly, it has become clear that the most significant ways to reduce the AIDS pandemic is to educate people on changing their behavior and their lifestyles. NIH is to be commended for its work in these areas but more needs to be done.

PREPARED STATEMENT

This subcommittee, Mr. Chairman, has taken the lead directing NIH to report to you on its specific goals, to raise its expenditures for health and behavior research from its current proportion. We are grateful for your support of this important area of study and we urge you to keep up the pressure. Thank you very much.

Senator ADAMS. Thank you very much, Doctor. How much money are you recommending in fiscal year 1991 for behavioral research at NIH and ADAMHA?

Dr. FOWLER. We have not been specific. We simply indicate that 3 percent is an inadequate proportion and we recommend that NIH be urged to increase the proportion within its recommended expanded budget.

[The statement follows:]

STATEMENT OF RAYMOND D. FOWLER

Mr. Chairman and distinguished members of this panel, thank you for this opportunity to testify on behalf of the American Psychological Association. The A.P.A. represents nearly 102,000 researchers, educators and clinicians, over 49% of whom report that some portion of their work involves research. It is on that subject that I want to address you today. I have served as the Chief Executive Officer of APA for two years, following a thirty-year academic career at the Universities of Alabama and Tennessee. I have thus observed the scientific research landscape from different vantage points and welcome this opportunity to offer suggestions to this Subcommittee as you make funding decisions for Fiscal Year 1991.

I will address three topics in this brief statement: the need for additional funding for NIH and the Alcohol, Drug Abuse and Mental Health Administration, both for non-AIDS and AIDS research; the need to increase the proportion of research that is behavioral in nature; and the critical role the federal government plays in encouraging young people to pursue careers in science.

With the exception of a few national priorities, critical aspects of the NIH budget have not seen much growth in recent years. For Fiscal Year 1991, the Administration's proposed NIH budget is $7.9 billion, a 4.7% increase over FY 1990. But this increase would not allow NIH to support fully its current level of funding, falling nearly $400 million short of the NIH's estimate of current services. A total of 123 new investigator-initiated grants will be awarded: but with 28 new awards going to genome research and 118 for AIDS, other areas will see a decrease. Fewer than one in five approved competing grants will actually be funded. Awards will be cut between 10 and 14 percent from approved levels, with higher negotiated reductions applied to competing grants. This policy makes it very difficult for research scientists and university centers to make economic plans and budgeting decisions. Cuts of this magnitude will not result in cheaper research, but LESS research. As strong advocates of AIDS research, we feel it is important to note that non-AIDS research dollars must be increased, not sacrificed to pay for AIDS funding expansions.

ADAMHA does not fare much better than NIH in the Administration's proposed budget. The President has proposed a slight funding increase for the ADAMHA Institutes for FY 91, but the proposal falls short of maintaining current service levels. The non-AIDS research budget is about 30% of ADAMHA's total proposed allocation of $776.8 million, spread across the three research institutes. The proposed number of new and competing grants is reduced by almost 31% from FY 90. Like NIH, ADAMHA will average a 20% award rate for new grants, down from 33% this fiscal year; that means only 1 in 5 peer-reviewed, approved research projects can be funded. Renewed grants will also be subject to downward negotiations.

We are asking this Subcommittee to reassess the priorities reflected in the President's budget. Our nation and its policymakers depend on NIH and ADAMHA research in making important budget and policy decisions. Scientists, physicians and patients depend on the research to deal with our most pressing health problems. We urge your support of funding levels that will sustain the progress in these research institutes, and that will continue to yield solutions to many of our gravest national problems.

APA supports increasing the NIH allocation to remove the specter of downward negotiations. If the Administration recommended fully funding all grants and centers, its request would be nearly $8.6 billion. We also support increasing to 30% the number of new competing grants that can be funded, which would bring the total NIH appropriation to $9.2 billion.

APA recommends a total ADAMHA appropriation of $1.197 billion. This recommendation would double the Administration's request for new project grants, and would allow ADAMHA to fund 40% of approved applications. The research institutes at ADAMHA are involved in more important work than can be emphasized in a brief statement, but a few projects must be mentioned.

Because of research at the National Institute of Mental Health, understanding the underlying mechanisms of mental disorders is at last becoming an approachable goal. We must not allow funding slowdowns and cuts to delay critical research results. Increases are needed for schizophrenia research, Alzheimer's Disease and child and adolescent disorders. Last year this Subcommittee directed NIMH to draw up a research plan to deal with child and adolescent mental disorders, and NIMH complied by sending out a report this week. APA certainly supports the goals contained in that report. Among the important behavioral research being funded by NIMH are projects that identify groups at risk for developing mental disorders and targeting prevention interventions to those groups. Those at high risk include children of an alcoholic or schizophrenic or depressed parent. This research can show how to break the familial cycle of mental disorders. APA recommends an appropriation of $502.1 million for NIMH research and support functions.

With the national focus on drug abuse, we all too often forget the enormous human toll taken by alcohol abuse. Because 10 percent of Americans are either alcoholic or have serious alcohol-related problems, it is imperative that Congress provide adequate research dollars for this institute. NIAAA-sponsored behavioral, social and neuroscientists are studying brain mechanisms involved in alcohol intoxication, reinforcement, tolerance and dependence, and have made significant progress. The American Psychological Association recommends $206.8 million for NIAAA research and demonstrations for FY 91.

While our nation has made progress in reducing the overall number of people who abuse drugs, drug abuse remains widespread, and the adverse health consequences connected with this terrible problem are increasing. The Drug Abuse Warning Network has reported that the number of people admitted to emergency rooms because of cocaine abuse increased by over 400% between 1984 and 1988. The number of people who died of cocaine abuse more than tripled during the same period. Mr. Chairman, the President's NIDA budget looks more like a skirmish than a real war on drug abuse. Research can provide our most important weapons. We recommend $465.7 million for drug abuse research and demonstrations for this institute.

As one of the co-chair organizations of the National Organizations Responding to AIDS (NORA), APA strongly endorses the $2.9 billion funding recommendations for AIDS and particularly the $764 million proposal for prevention activities at the Centers for Disease Control (CDC) and ADAMHA. Prevention must remain one of our chief priorities in dealing with this deadly illness, and it is clear that a number of populations have not heard or haven't adopted the message about reducing risky behaviors. This is why the research and research demonstration activities at ADAMHA are particularly important, and should be funded at $324 million.

The increase will restore the $20 million cutback in NIDA's drug abuse outreach demonstrations which are decimated by the President's proposal but are beginning to develop useful models for intervening with IV drug users, the fastest growing at-risk population. It would maintain the number of ADAMHA new and competing research grants at the FY 90 level, preventing the destabilization of research funding for AIDS behavioral and social science research. The randomized field trials of prevention interventions, recommended by the National Academy of Sciences, would be properly funded with this increase--projects critical to the identification of the most effective community-wide prevention strategies. These dollars would support the establishment of the mental health services research program at $12 million, an effort which is particularly important as a means of sustaining behavor changes. Finally, this increase will allow for sorely needed integration between researchers and service providers to insure a better collaboration and understanding between both groups, including the linkage of grants issued by ADAMHA and CDC in this area.

The issue of research training and clinical training is vitally important to the scientists at APA. Because the odds against obtaining funding at current appropriation levels are so great, there is a very real fear in the scientific community that young researchers will be unable to compete, and will turn to other careers. There is a basis for this fear. Last fall, APA commissioned a Rand Corporation study which reported that there had been a striking decrease in the proportion of awards to researchers under the age of 35. In the past decade we have watched funding for research decline little by little, and those small decreases add up to big problems. Not only is excellent peer-reviewed research going unfunded, but potentially brilliant scientific careers lie fallow. One action by the federal government which could help keep young scientists in research is an expansion of the research and clinical trainee programs at NIH and ADAMHA.

We applaud the Administration's proposal to support 12,020 National Research Service Award trainees at NIH. We would also recommend 250 additional research career awards, with a focus on behavioral science, bringing the total to nearly 1,800.

At ADAMHA we support clinical training projects in psychology and the other core mental health fields. These projects are designed to ensure the placement of mental health professionals in underserved areas of the country, and to improve the quality of training provided to those professionals. The training programs focus on priority service populations: first, severely mentally ill adults, including homeless adults; second, emotionally disturbed children and adolescents; and third, elderly persons with mental disorders. All of these populations are underserved generally, and in some areas of the country, ADAMHA-trained professionals are the only service providers. As you know, nearly all the mental health disciplines, including psychology, pay back the costs of their training with service in areas where they are most needed. This year the Administration has requested only $5 million for ADAMHA clinical training programs. This falls far, far short of meeting the tremendous need. We recommend $26 million for trainee programs at ADAMHA in FY 91, plus an additional $3 million for specific training in alcohol and drug abuse education.

I will close this statement by emphasizing a promising area of behavioral research that deserves additional support by the federal government. Health and behavior research is the study of how human behaviors can affect human health, and how to influence people to do what is good for them, and stop doing what is bad for them. This Subcommittee has directed several times that NIH increase the percentage of health and behavior research, which has hit a plateau of around 3% of research expenditures. NIH has a special responsibility to heed the findings of the Institute of Medicine's report Health and Behavior: A Research Agenda, which NIH cosponsored. This report identified lifestyle and behavioral factors as the major causes of death in the U.S. Similarly, it has become clear that the most significant way to reduce the AIDS pandemic is to educate people on changing behaviors and lifestyles. NIH is to be commended for its work in these areas, but more needs to be done. Your Subcommittee, Mr. Chairman, has taken the lead in this vital area, directing NIH to report to you on its specific goals to raise its expenditures for health and behavior research from its current proportion. We are grateful for this Subcommittee's support of this important area of study, and we urge you to keep up the pressure.

We understand that you are hearing from many groups today, with many different recommendations on ways you should divide the Subcommittee's money. We know that health programs compete for dollars with one another, and with education programs, and in a larger way, compete with other federal spending priorities like defense and the space station. If I could leave you with one thought, it is that NIH and ADAMHA have broad mandates to remove from our nation and its people the scourge of debilitating diseases and harmful habits, and the researchers are making progress. There will be breakthroughs: spending will dictate how quickly those breakthroughs will occur. We appreciate your past support of NIH and ADAMHA, and urge additional support in FY 91. Thank you.

SUBCOMMITTEE RECESS

Senator ADAMS. Thank you very much for your testimony. We appreciated it.

The subcommittee will stand in recess until 9:30 a.m., Tuesday, March 27. At that time, the subcommittee will continue public witness hearings on the administration's fiscal year 1991 budget request, the hearings will be held in room SD–192.

[Whereupon, at 11:45 a.m., Wednesday, March 21, the subcommittee was recessed, to reconvene at 9:30 a.m., Tuesday, March 27.]

DEPARTMENTS OF LABOR, HEALTH AND HUMAN SERVICES, AND EDUCATION AND RELATED AGENCIES APPROPRIATIONS FOR FISCAL YEAR 1991

TUESDAY, MARCH 27, 1990

U.S. SENATE,
SUBCOMMITTEE OF THE COMMITTEE ON APPROPRIATIONS,
Washington, DC.

The subcommittee met at 9:45 a.m., in room SD–192, Dirksen Senate Office Building, Hon. Brock Adams, presiding.

Present: Senator Adams.

NONDEPARTMENTAL WITNESSES

Senator ADAMS. The subcommittee will come to order. Good morning to you all. Welcome. We hope you will have a nice day, and if not, we hope it is bearable.

This morning, we will continue with a fourth of 6 days of public witnesses' testimony focusing on programs funded by the Subcommittee on Labor, Health and Human Services, Education and 20 related agencies.

During these several sessions, this subcommittee will hear testimony from approximately 150 witnesses. It is a matter of regret, and I mean that, to all members of the subcommittee that we have had to limit the number of witnesses that we will be able to hear this year.

You have all been understanding about our time constraints, and I do want to assure you that witnesses who have their testimony to the subcommittee staff by April 9 will have that testimony put into the hearing record.

In order to help us stay on schedule, we are going to use the red light, green light system. As you know, based on the letter you received from Chairman Harkin, each witness has 3 minutes in which to present his or her oral testimony. When the red light goes on, your 3 minutes have expired. We need to ask each of you to conclude your remarks when the red light goes on so that each witness will have a fair and equal opportunity to be heard.

I would like to welcome all of you to the committee. I might state that we have several Senators who have requested that they be heard this morning. We are in the process of voting on the Clean Air Act as indicated by the lights, and the vote on that has not been completed. I have already gone over to vote, and the others are voting and will be here as promptly as possible. So, under those conditions, I will call the first witness and then I may have to break in the order of witnesses in order to give comity to the Senators who will be on their way.

At some point in the morning, I have a statement to make and there is a break in the morning for a celebration for President Eisenhower over in the House side. I will not leave for that because all of you are here. I will be gone for only a few minutes, and I hope to have somebody substitute for me, but in any event, I will be back in a few minutes if I do have to leave. So, we will continue right through the witnesses so that we can complete them this morning. That's why I said to all of you, I hope you have a nice day, and we hope not to keep you waiting too long.

STATEMENT OF THOMAS F. BURKS, PROFESSOR, UNIVERSITY OF ARIZONA COLLEGE OF MEDICINE, ON BEHALF OF THE AMERICAN SOCIETY FOR PHARMACOLOGY AND EXPERIMENTAL THERAPEUTICS

ACCOMPANIED BY:

ELLIOT VESELL, PROFESSOR OF PHARMACOLOGY, PENNSYLVANIA STATE UNIVERSITY COLLEGE OF MEDICINE

KARL H. BEYER, JR., VISITING PROFESSOR, PENNSYLVANIA STATE UNIVERSITY COLLEGE OF MEDICINE

Senator ADAMS. Our first witness this morning is Dr. Thomas F. Burks, University of Arizona College of Medicine and American Society of Pharmacology and Experimental Therapeutics.

Dr. Burks, we welcome you and I will say to all the witnesses that if you wish your statement placed in full in the record, please so indicate to the chairman and I will do so, and then you can summarize or proceed in any way that you wish.

Dr. Burks, welcome to the committee.

Dr. BURKS. Thank you, Mr. Chairman, and thank you for providing us with this opportunity to testify before your subcommittee. I am Dr. Thomas F. Burks, professor and head of the department of pharmacology and associate dean for research at the University of Arizona College of Medicine.

I am accompanied by Dr. Elliot Vesell, Evan Pugh, professor of pharmacology at the Pennsylvania State University College of Medicine and by Dr. Karl H. Beyer, Jr., visiting professor at the Pennsylvania State University College of Medicine, former head of research at Merck, Sharp & Dohme, and the former winner of the prestigious Lasker award.

We represent the American Society for Pharmacology and Experimental Therapeutics [ASPET], of which I am president elect. Dr. Vesell serves as chairman of our society's public affairs committee.

ASPET is a scientific society of over 4,000 scientists involved in research and teaching at leading academic and research institutions, in government laboratories and in the pharmaceutical and biotechnology industries.

Pharmacologists investigate cellular mechanisms of drug action and design new medicines that cure, ameliorate or prevent disease, and also that act as tools to understand body functions. We develop new knowledge that provides cures for the diseases that are killing us.

ASPET is a constituent society of the Federation of American Societies for Experimental Biology. We have reviewed and heartily endorsed the testimony that Dr. William L. Dewey, president of FASEB, presented to your subcommittee on March 22.

While research in pharmacology is increasingly funded by the pharmaceutical and biotechnology industries, the Federal Government, through the National Institutes of Health and the Alcohol, Drug Abuse, and Mental Health Administration, still provides most of the support. Our society is grateful to your committee for the strong support you have given NIH and ADAMHA over the years. It has made a very real difference in the battle against disease.

We strongly believe that President Bush's fiscal year 1991 budget request for the National Institutes of Health and the Alcohol, Drug Abuse, and Mental Health Administration is woefully inadequate, especially in regard to extramural and investigator-initiated grants. These grants are the hallmark of America's biomedical research effort. The extramural grant program has sponsored the research leading to the major medical discoveries of the past 50 years.

We are concerned that some of the funding that is being provided in the President's budget is detrimental to good science. The President is proposing up to a 14.6-percent cut in every new and competing NIH grant. This is called a downward negotiation, but it is really a meat cleaver approach to the reduction of budgetary support for science.

We endorse, at a minimum, the recommendations of the ad hoc group for medical research funding. Those recommendations call for the full funding of 30 percent of approved research project grants at NIH, which will raise the number of new awards to about 6,000.

The number of new and competing grants at NIH and ADAMHA should be greatly increased for several reasons. Biomedical research is cost effective, biomedical research enhances America's competitive position in the world economy. The severe cuts in new and competing grants presently discourage young people from considering careers in biomedical research, and excellent scientific opportunities are being missed, and as a result, human suffering will increase.

PREPARED STATEMENT

In summary, we are testifying that the best science in this country requires a $1.3 billion increase above the administration request. That would allow us to fund fully, 6,000 new and competing renewal grants.

Thank you, Mr. Chairman.

[The statement follows:]

STATEMENT OF DR. THOMAS F. BURKS, PRESIDENT-ELECT, DR. ELLIOT S. VESELL, CHAIRMAN, PUBLIC AFFAIRS COMMITTEE, AND DR. KARL H. BEYER, JR.

Mr. Chairman and members of the subcommittee, thank you for providing us an opportunity to testify before your subcommittee. I am Dr. Thomas F. Burks, professor and head of the department of pharmacology at the University of Arizona College of Medicine. I am accompanied by Dr. Elliot S. Vesell, Evan Pugh Professor and chairman of the department of pharmacology at the Pennsylvania State University College of Medicine and Dr. Karl H. Beyer, Jr., visiting professor at the Pennsylvania State University College of Medicine, former head of research at Merck Sharp & Dohme, and a former winner of the prestigious Lasker Award. We represent the American Society for Pharmacology and Experimental Therapeutics (ASPET), of which I am president-elect. Dr. Vesell serves as chairman of our Society's Public Affairs Committee.

ASPET is a scientific society of over 4,000 scientists involved in research and teaching at leading academic and research institutions, in government laboratories, and in the pharmaceutical and biotechnology industries. Pharmacologists attempt to design new medicines that cure, ameliorate, or prevent disease and also that act as tools to understand body functions. ASPET is a constituent society of the Federation of American Societies for Experimental Biology. We have reviewed and heartily endorse the testimony that Dr. William L. Dewey, president of FASEB, presented to your subcommittee on March 22.

While research in pharmacology is increasingly funded by the pharmaceutical and biotechnology industries, the federal government, through the National Institutes of Health and the Alcohol, Drug Abuse and Mental Health Administration, still provides most of the support. Our Society is grateful to your subcommittee for the strong support you have given NIH and ADAMHA over the years. It has made a very real difference in the battle made against disease.

We strongly believe that President Bush's fiscal 1991 budget request for the National Institutes of Health (NIH) and the Alcohol, Drug Abuse and Mental Health Administration (ADAMHA) is woefully inadequate, especially in regard to extramural, investigator-initiated grants. These grants are the hallmark of America's biomedical research effort. The extramural grant program has sponsored the research leading to the major discoveries of the last 50 years.

The President is proposing to fund 5,095 new and competing research project grants at NIH, down from the more than 6,400 new and competing grants funded in 1987. At ADAMHA, the situation is even worse. The Administration is calling for funding only 604 new and competing grants, a 31 percent cut from the fiscal 1990 level.

We are also concerned that some of the funding is provided by using gimmicks that are detrimental to good science. The President is proposing a 14.6 percent cut in every new and competing NIH grant. The Administration calls this a "downward negotiation," but there is no negotiation at all. This meat cleaver approach to budgetary constraints ignores the recommendations of scientific review panels, reduces the scope of proposed research, and frequently makes it impossible to complete the research project effectively.

We endorse, as a minimum, the recommendations of the Ad Hoc Group for Medical Research Funding. Those recommendations call for the full funding of 30 percent of approved research project grants at NIH, which will raise the number of new awards to about 6,000. In view of the enormous needs for progress in the treatment of disease, we believe that an award rate of 45 to 50 percent achieved over the next two to three years is much more appropriate. We also endorse the Ad Hoc Group's recommendation for ADMAHA, which calls for 1,200 new and competing grants and an award rate twice that proposed by President Bush. Our Society urges the subcommittee to specify in its report to the Senate both the number and total dollar amount of new and competing grants it recommends funding.

We are also specifically concerned about the President's request for the National Institute of General Medical Sciences. The proposed 4.7 percent increase over fiscal 1990 is inadequate. Within the request, only a 4.3 percent increase is slated for the Institute's superb Pharmacological Sciences program. This amount is well below the biomedical inflation rate and will mean fewer important scientific advances and more human suffering.

The number of new and competing grants at NIH and ADAMHA should be greatly increased for several reasons:

Biomedical research is a cost-effective investment; biomedical research enhances America's competitive position in the world economy; the severe cuts in new and competing grants presently discourage young people from considering careers in biomedical research; and excellent scientific opportunities are being missed, and as a result, needless human suffering will continue.

Investment in pharmacological research is extremely cost effective. Chemical treatments for ulcers, gout, high blood pressure, mental disorders and countless other human maladies have significantly reduced hospital stays, increased productivity, and greatly reduced suffering. Improved and less intrusive drugs and other therapies must be developed to reduce health care expenditures. Despite the obvious demand for better, cheaper medical care, America currently spends less than two percent of its health budget on research. We believe that a more substantial investment would be well advised. Most other industrialized societies spend more.

No science and technology intensive enterprise will remain competitive and healthy if America's minuscule investment in research is maintained for long. We are on the threshold of a new era of astounding medical progress. The research findings of the past decade are opening new vistas of opportunity and basic research discoveries are being funnelled to the clinic and bedside faster than ever before.

America always has been, and continues to be, the world leader in biomedical research. However, our lead is slipping fast. At our institutions we are seeing signs that do not bode well for the future. More of our graduate students are from foreign countries and often return home once their training is complete. Qualified American students are not being rejected by universities, but rather qualified American students are rejecting careers in biomedical research.

Graduate students see the downward trend in biomedical research funding and decide that other fields offer better chances of career success. Students see their mentors and professors submit excellent research proposals, some rated as high as the 10th and 11th percentile, only to have those proposals go unfunded. The often violent harassment of researchers by anti-vivisectionists also has made the field much less attractive.

Failure of Congress and the Administration to provide the biomedical research community with the resources to remain competitive in the educational marketplace will have catastrophic results in the decades ahead. This is a long term problem that defies short-term approaches. That is why we advocate a steady increase in the number of new and competing awards and a commitment by Congress and the Administration to fully fund these grants.

Lastly, but probably most importantly, without an increase in new and competing grants, opportunities to make significant progress against the killers and cripplers of mankind will be delayed or missed. Sickness and disease take an enormous physical, social, and economic toll on the lives of our citizenry. To do less than our best is unacceptable. With the lessening of tensions with the Soviet bloc we can now afford to do more. We must meet the challenge by finding the will and the way to do it.

RESEARCH

Senator ADAMS. Thank you, Dr. Burks. You stated that America currently spends less than 2 percent of its health budget on research. Can you give me an idea or close estimate of what the other industrialized nations are spending?

Dr. BURKS. In any industry, the investment in research should be approximately 10 percent of the total budget, expenditure budget. We have an expenditure budget of approximately $50 billion for research and for medical care, and we should have a larger budget for research.

The other industrialized nations, notably Japan, West Germany, and others, are spending closer to 5 to 7 percent of their budgets.

Senator ADAMS. Thank you very much, Dr. Burks.

STATEMENT OF C. DOUGLAS MAYNARD, WAKE FOREST UNIVERSITY, THE CONJOINT COMMITTEE ON DIAGNOSTIC RADIOLOGY

Senator ADAMS. Our next witness is Dr. C. Douglas Maynard, Wake Forest University, Winston-Salem, NC, the Conjoint Committee on Diagnostic Radiology.

Welcome, Dr. Maynard, we are pleased to have you with us this morning, and as I indicated before, if you wish to summarize your statement, it will be placed in the record, or you may read it, whichever you prefer.

Dr. MAYNARD. Good morning. First, I would like to thank you for allowing us to present this morning.

I am Doug Maynard, chairman of radiology at Wake Forest University. I am here on behalf of the Conjoint Committee on Diagnostic Radiology, and I currently serve as chairman of the executive committee of that group.

The conjoint committee is composed of three organizations: the American College of Radiology, Association of University Radiologists, and the Society of Chairman of Academic Radiology Departments, and it is a joint committee. These organizations formed this committee in 1978, the sole purpose, to promote and support the advances of diagnostic, radiology research and research training.

Over the past 15 years, the field of diagnostic radiology has participated in truly remarkable advances in the diagnostic capabilities of medicine. These advances have come as a result of extensive basic and clinical research, much of which has been supported by appropriations recommended by this committee.

Today, medical imaging procedures account for or contribute directly to the final diagnosis in more than 75 percent of all hospital admissions. Computer tomography, nuclear medicine, ultrasound, magnetic resonance imaging, and angiography are routinely employed in the diagnostic workup of patients with heart disease, cancer and stroke.

Diagnostic, radiology procedures extend across the boundaries of virtually all medical disciplines, from pediatrics to geriatrics, from family practice to neurosurgery. Precise, noninvasive diagnostic procedures and those which can accurately determine responses to specific treatments are vital to medical practice. Although our radiological procedures currently provide such information, we are convinced that our techniques can be further refined and even dramatically improved. However, much research will be needed in order to realize the full potential of radiological techniques.

Mr. Chairman, last year this subcommittee recognized that the overall progress in the field of diagnostic radiology is seriously hampered by the fact that the NIH, the most prestigious, research-focused institute in the world, has no separate, identifiable research program in this area.

Based upon this subcommittee's recommendation, Congress, last year, directed the NIH to allocate up to $2 million to establish a separate, intramural research program in diagnostic radiology. This intramural program would permit the NIH to conduct its own basic research in diagnostic radiology, provide a center for the training of new young investigators, and assist with and participate in the programs of the various other research institutes.

Although there has been some activity on the part of NIH to respond to this directive, the Conjoint Committee on Diagnostic Radiology is concerned that the importance of a separate, identifiable research program in diagnostic radiology may not be fully understood. Only with a clear presence in the form of a stand-alone, diagnostic imaging research initiative at the NIH, can this field attract the essential researchers, trainees and staff to build the caliber of program we believe worthy of the NIH.

PREPARED STATEMENT

We would request, therefore, Mr. Chairman, that this subcommittee reemphasize to the NIH the importance of this program, the necessity for a clear and separate identity with the NIH and the urgency that appropriate funds be allocated to establish and maintain a viable stand-alone, intramural research effort in diagnostic radiology.

Again, I would like to thank you for allowing us to present.

[The statement follows:]

Statement of C. Douglas Maynard, M.D.

Mr. Chairman and members of the subcommittee, my name is C. Douglas Maynard and I am Professor and Chairman of the Department of Radiology at the Bowman Gray School of Medicine. I am here today on behalf of the Conjoint Committee on Diagnostic Radiology.

By way of background, the Conjoint Committee is composed of representatives from the American College of Radiology, the Association of University Radiologists, and the Society of Chairmen of Academic Radiology Departments. The idea of drawing these organizations together for a common purpose was conceived in 1978. And while our field is noted for the rapid pace of new knowledge and innovations it generates, our common purpose has held clear and steady: that is, to promote and support the advancement of diagnostic radiology research and education.

Over the past 50 years, Mr. Chairman, the advances in medicine have been truly remarkable. These advances came as a result of extensive basic and clinical research, much of which was supported by appropriations recommended by this Subcommittee. The field of diagnostic radiology has played a significant role in these advancements and has itself experienced more dramatic changes in the past two decades than any other specialty in the field of medicine.

Today, for example, medical imaging procedures account for, or contribute directly to, the final patient diagnosis in more than 75 percent of all hospital admissions. And these procedures have rapidly extended to the outpatient environment as well.

But at no time in the past has the field of radiology offered more opportunities for research that could directly enhance our ability to diagnose diseases that continue to plague society. Such areas as nuclear medicine, computed tomography, ultrasound, nuclear magnetic resonance imaging, and what is being called "filmless" radiology are leading this new progress in diagnostic medicine.

The promise these and other advancements hold cross the boundaries of practically every scientific and medical discipline from pediatrics to geriatrics and from family practice to microsurgery.

Mr. Chairman, last year this Subcommittee recognized that overall progress in the field of diagnostic radiology is seriously hampered by the fact that NIH, the most prestigious research institution in the world, has no single research focus in this area.

Nowhere within the intramural programs at NIH was there a diagnostic radiology laboratory to carry out some of this important research or to assist the various research institutes.

Following this Subcommittee's recommendations, Congress last year directed NIH to allocate up to $2 million to establish an intramural program in diagnostic radiology. This intramural program would permit NIH to conduct its own basic and applied research into imaging processes, collaborate with other intramural research teams, provide a center where new investigators could learn the latest research techniques, and assist the extramural research programs of the various research institutes.

Despite very explicit directives from Congress, NIH seems headed in an entirely different direction. Plans are underway to use the bulk of the funds you provided to purchase a magnetic resonance imaging device. And instead of establishing an independent research laboratory—capable of conducting basic research and contributing to the knowledge base of not only radiology, but of other disciplines as well—NIH plans to create a small postdoctoral training program, where a handful of trainees would be farmed out, in an unorganized fashion, to a variety of existing laboratories across the NIH campus.

In effect, NIH has evidently chosen to ignore a very clear mandate from Congress—a mandate that, in our opinion, would strengthen NIH's own scientific capabilities and its overall research mission.

RECOMMENDATION

Mr. Chairman, we urge this Subcommittee to intercede and put this effort back on its original track. NIH should be directed to use the appropriated funds for the purpose for which this Subcommittee intended—to establish a free-standing and focused intramural research program in diagnostic radiology.

Thank you, Mr. Chairman. I would be glad to answer any questions you may have.

LOCATIONS OF PROGRAM

Senator **Adams**. Thank you, Doctor. Last year, this committee provided $2 million to the Office of the Director of NIH, to establish this program that you have referred to in your testimony. Why hasn't NIH made better progress in this program?

Dr. **Maynard**. I think that they have been trying, specifically, to decide where the program should be located within the NIH, and we are going to be meeting with them on April 13, to work with the staff and to see exactly where it should be located. We would like to see them make better progress.

Senator **Adams**. Tell them location is not quite as important as action.

Dr. **Maynard**. And we would like identity.

Senator **Adams**. Yes; I can remember as a secretary, having people say that they could go into a particular office, but if they did, we would have to paint out one of the windows because they were only entitled to a one-window office rather than a two-window office, and I do not want that kind of thing to be happening here. So I hope you are located well and I hope you will inform the committee if you are not. It is a pleasure to have you with us this morning.

STATEMENT OF HON. J. ROBERT KERREY, U.S. SENATOR FROM NEBRASKA

Senator **Adams**. I see that Senator Bob Kerrey has arrived. Senator Kerrey, you are granted exalted status here this morning as a member of this body and as a colleague and friend. We are very pleased to have you with us this morning. I cannot think of anyone that I have more respect for in the field of medicine, and a person who has both personal experience as well as broad experience as a Governor of the State.

Senator Kerrey, it is a great pleasure to have you with us this morning.

Senator **Kerrey**. Thank you. I noted the subject matter. I wish that I were here to testify on health. I am here, actually, to offer testimony on impact aid. I also would like to submit Senator Exon's testimony for the record. He has an Armed Service Committee meeting at the moment, and is not able to present it himself.

Senator **Adams**. Without objection, the testimony of Senator Exon will appear on the record as given.

Senator **Kerrey**. Similarly, I would like to offer the full text of my comments for the record, and then simply offer some summary statements on impact aid.

Senator **Adams**. Without objection, the entire statement will appear in the record as given.

Senator **Kerrey**. Impact aid is one of those items that is an easy target for reductions. It is one of those programs that, once established, people forget why it was there. It remains then, for those of us who live in States that are close to Federal facilities, to come every single year and explain why it is important to maintain this impact aid, both the 3(a), the 3(b) categories.

We have four districts that have over 60 percent of their students that fall in the 3(a) or 3(b) categories. There are at least 15 school districts that are eligible for impact aid, and I would just offer, Mr. Chairman, that impact aid, I believe, is even more important in 1990–91, as a consequence of a decade of shifts from the Federal to local governments, reinforced by a number of actions that, on the surface, do not appear to be connected. We have eliminated revenue sharing, for example. We have, on an inflation basis, decreased our support for education, requiring States and local school districts to pick up all the slack of the decreased Federal commitment.

I do not have to tell you what has occurred in transportation. The Secretary, 2 weeks ago, presented the transportation plans, which was essentially saying, local people must pay for any improvements in our infrastructure. There are proposed cutbacks in waste water treatment grants. The list is fairly long, where the Federal Government is essentially saying, we are not going to be a partner. We are going to talk, but we are not going to be a partner with the local communities.

PREPARED STATEMENT

Therefore, this particular effort becomes even more important, and I appreciate, Mr. Chairman, you giving me the opportunity to testify. I will be arguing on the floor as well, and will be talking with other Members of the Senate and trying to convince them that this rather small and rather silent program is an issue of fairness. We ought to fund it fully, and we ought to consider the negative consequences for the school children in the districts that are close to Federal facilities if we do not provide that full funding.

[The statement follows:]

Statement of Senator J. Robert Kerrey

Mr. Chairman, I would like to thank you and the Committee for allowing me this opportunity to testify on behalf of a program fundamental to educational excellence and opportunity in the Nation, and particularly in the State of Nebraska. I am also here today on behalf of Senator Exon, who, due to other obligations was unable to join me here today. He has asked me to provide the Subcommittee with his testimony, and I ask that his statement be included in the hearing record.

Almost four decades ago, the 81st Congress formally acknowledged a key responsibility to children and school districts across the nation. By enacting Public Law 81-374, the Impact Aid program, the federal government recognized its duty to reimburse school districts for the property tax foregone because of federal ownership, and for lost revenues from "federally-connected" parents.

This was no federal giveaway. It was not charity. This was federal responsibility.

Few localities rely on impact aid as heavily as Nebraska. With the Strategic Air Command, Offutt Air Force Base and a number of Native American reservations within our borders, Nebraska cannot afford for the federal government to renege on its fundamental duties. These schools are also affected by the fact that the State of Nebraska continues to rely heavily on property taxes as the primary source of school funding. Any loss of revenue as a result of federal activities would be devastating without the compensation granted under the impact aid program.

An analogy is often made between individual property holders and the federal government when it owns land in a school district. The analogy is apt and useful, I think, in demonstrating that the federal government must own up to its responsibilities when it removes valuable property from a district's tax base.

Unfortunately, the comparison breaks down in its practical application; while a property owner faces severe penalties for refusing to pay property taxes owed, the federal government can cut impact aid funding at will. And it has.

Over the past decade, the impact aid program, like so many other essential education programs, has been slashed. Although President Bush has broken with the Reagan Administration record of seeking to eliminate funding for category "b" students in his fiscal year 1991 budget, his requested amount is still far below what these students deserve. The President entirely neglects to take inflation into account in his requests for category "a" students and Section Two by requesting amounts equal to the amounts appropriated by Congress for fiscal year 1990. Although the assistance appropriated under this program has decreased in real terms, the costs of educating children has increased.

It is estimated that 15 Nebraska school districts will be eligible for impact aid this year. In four of those districts—Bellevue, Macy, Santee and Winnebago—over 60 percent of the students fall under the 3(a) or 3(b) categories. As such, every cut in impact aid can be devastating to these schools. Every increased dollar is sorely needed.

Mr. Chairman, as you know, impact aid funds are not a luxury for these school districts. These funds pay for bread-and-butter operating costs, for textbooks, for teacher salaries. I urge upon the Subcommittee today, that federally-impacted schools can absorb no more cuts, and, in fact, that an increase in financial support for these schools is essential.

In a year that there has been so much concern about our Nation's educational system, it is sad that we are unwilling to reach into our pockets for our children's education. We run the risk of losing a generation of children.

Let us act on this growing consensus with a renewed commitment to education funding. Let us begin by fulfilling the duties of the federal government as a local property owner and employer. Let us again commit ourselves to adequate support for impact aid.

Thank you Mr. Chairman and members of the Committee.

PREPARED STATEMENT OF SENATOR EXON

Senator ADAMS. The subcommittee has received a statement from Senator Exon which he would like inserted in the record.

[The statement follows:]

STATEMENT OF SENATOR JIM EXON

Mr. Chairman and members of the Committee, I am pleased to have this opportunity to present to you my strong and unwavering support for several programs which fall within the jurisdiction of this subcommittee.

First, I would like to address the needs of the Impact Aid program. As you may be aware, I have been a strong supporter of this program for many, many years. Nebraska is somewhat unique in that we incorporate just about all the categories available under the program. We have approximately twelve districts that receive Section 2 payments for federally owned land such as Harlan County Reservoir and Sherman Reservoir. Within Section 3 of the program, Nebraska educates military and civilian students from Offutt Air Force Base which is the SAC Headquarters; Indian students from three tribes, the Winnebago, the Omaha, and the Santee; children residing in low-income housing units; as well as various and scattered "3(b)" students eligible under this program due to federal projects such as the U.S. Meat and Animal Research Center in south central Nebraska.

Impact Aid funding is vital to many of the school districts in my state. Bellevue Public Schools depends on Impact Aid for approximately 35 percent of their operating budget. Macy, Santee, and Winnebago School Districts depend on Impact Aid for over half of their operating budgets. Mr. Chairman, we must fully fund this program. The Impact Aid program provides essential, basic funding to these schools. I want to stress, this is not frivolous "extra" spending. This money finances bottom line items for schools, such as books, teachers' salaries, desks, and equipment. This money does not ensure that these schools have top of the line new equipment every year or the latest in new technology. It does ensure that these schools will remain open and available to educate our children. In many cases, these school districts are operating in old worn out buildings and "getting by" in terms of equipment.

If I may, I would like to relate the situation of one of the other school districts in my state that receives Impact Aid. Papillion-LaVista Public Schools have maintain a relatively constant percent of impaction with respect to the Average Daily Attendance - 36.2 to 38.5 percent impaction. However, their Impact Aid funding, as a percent of total budget has decreased, from 8.5 percent to 4.3 percent. That's a 50 percent decrease. Their cost per pupil has increased from $1,565.23 to $ 2,954.59. That's almost a 100% increase. Although the assistance appropriated under this program has decreased in real terms, the costs of educating children has increased. If we want to stabilize and hopefully improve our educational system in this country, we will not do it by cutting basic, bottom line educational funding.

In the past, the Subcommittee has tried to redirect dollars in this program to those districts that are most in need of the dollars. While I certainly applaud the efforts of the Subcommittee, I submit that changes of that magnitude need to be made by the authorizing committee. I would hope that the subcommittee will refrain from suggesting changes that will eliminate two-thirds of the eligible schools until after the authorizing committee has a chance to closely study and re-evaluate the total program. The funding formula set up in the 1987 reauthorization of this program will work if the program is given full funding.

I also support increased funding for the Impact Aid School Construction program. I believe it goes with out saying that our commitment to this program has been a joke over the last several years. If we are lucky, this fund will finance one or two projects while we have over a hundred on the waiting list. If we want our children to go to school, we have to ensure that they have adequate facilities to go to. We cannot demand our students be the best in the world if they have less than reasonable accommodations.

Mr. Chairman, I would also like to lend my support and encourage increased funding for the State Student Incentive Grant (SSIG) program and the Star Schools program. As you know, the President zeroed out both of these fine programs.

The SSIG program provides one of the best deals as far as student aid goes. This program requires at a minimum a dollar for dollar match from the state. Therefore, the student is receiving at least $2 for every federal dollar invested. What other federal program offers that kind of "bang for the buck." We must also work to shift the student aid balance back towards more grants and less loans, especially for the lower income families. Students today are coming out of school thousands of dollars in debt. They can't afford to be teachers, or social workers, or public servants. We must reverse that trend.

The Star Schools program offers diversified curriculum to our smaller schools, especially those in rural areas. Nebraska belongs to the multi-state SERC Consortium. Because of this association, students in Nebraska have access to Japanese, Russian, Advanced Economics, Probability and Statistics, and Advance Science Seminars. Teachers have access to AP Economics for Teachers, AP Calculus for Teachers, and some wonderful in-service seminars. Many schools in Nebraska would not be able to offer this kind of curriculum without the assistance of the Star School program. Distance learning is exciting and effective. We must continue this opportunity.

Lastly, Mr. Chairman, I would like to touch on the Community Services Block Grant program. Again, President Bush eliminated all funding for this program. I find that a little ironic in light of his proposal to increase funding for the Head Start program. In Nebraska, many of the Head Start programs are administered through Community Action Agencies, which in turn are funded by the CSBG program. You can throw all the money you want at a program, but if there's no network in place to run the program, the money is not going to do any good.

The Community Services Block Grant funds a variety of programs that, at least in Nebraska, tend to catch those that would otherwise "fall through the cracks" of many of the other social and family assistance programs. Although the economy in the rural areas is beginning to pick up, there are still many families in need of some assistance. The CSBG program has proved to be effective in rural areas and in many cases, the assistance provided does not carry with it the stigma of "welfare". Maintaining dignity is very important to Nebraska's families who, up to now, have always been self sufficient.

As a member of the Armed Services Committee and the Budget Committee, I believe that this is a watershed year for federal funding. I believe that we will have a small "peace dividend", and I support moving some of that money into education and other human resource programs.

These programs are ones that provide basic services to young and old alike. We cannot forsake the more vulnerable individuals of our society by allowing the President's budget recommendations to become law.

Thank you Mr. Chairman and members of the Committee.

Senator **Adams**. Thank you very much. I find that each year, the administration proposes to take this out, and each year we have to put it back in, and I want to tell you that I will be one of those working with you to put impact aid back into the budget. It is essential. We have the same type of State in many ways, small counties that without this type of assistance, simply the whole level of education drops.

We appreciate your being here this morning, and I hope to hear you another morning on health matters.

Senator **Kerrey**. I appreciate it. Since I have got the microphone sitting in front of me, I would offer this, in 60 seconds' time. I was very disturbed by the New York Times article this morning, talking about the prohibition of fetal tissue research that we are currently maintaining at NIH. I just think it is a tragedy that we block, for ideological reasons, any kind of research, whatsoever. And it is clear that human beings are being adversely affected by this. I regret it and would offer one voice in support of eliminating that restriction.

Senator **Adams**. Thank you very much, Senator Kerrey. We appreciate your being here this morning.

STATEMENT OF HON. JOSEPH I. LIEBERMAN, U.S. SENATOR FROM CONNECTICUT

Senator **Adams**. I see that Senator Lieberman has now arrived, also. Welcome and we are pleased to have you with us here at the committee this morning, and we will be very pleased to hear your testimony.

Senator Lieberman.

Senator **Lieberman**. Thank you very much, Mr. Chairman. I appreciate the opportunity to testify before you this morning on three matters that are of critical importance to Connecticut, and I believe the rest of the Nation as well.

The first, I will touch on only briefly, because my colleague, friend, and classmate, Senator Kerrey, has just talked about impact aid. It affects Connecticut as well.

We have one community, Groton, CT, in the area of nuclear submarine base and 46.3 percent of the students in the Groton public school system are federally connected. In fact, the shortfall per Federal student every year is $1,621.

I think there is a duty we have as a nation, to ensure not only that the children of military families receive quality education, but that the local school districts do not go broke trying to provide them quality education. I thank you, Senator Adams, for your indication of support for impact aid, and I am glad to do anything I can to make that possible.

The two other programs I want to talk about are low-income home energy assistance and Lyme disease. The LIHEAP Program, low-income home energy assistance program, is critically important to hundreds of thousands of people throughout this country—the poor, the elderly, the disabled who simply cannot afford the basic heat for their shelter that we would associate with a minimally, civilized life.

And this program, LIHEAP, is one that works. It is a governmental assistance program that works, with very little bureaucracy, providing direct services. People depend on it, everybody supports it, but there is not enough money appropriated for it. And we saw that dramatically last December, when we had the record cold month and oil prices shot up, I think, exorbitantly.

But that is not before us at the moment. What happened last December, is that LIHEAP was there to help a lot of people. But as a result, the LIHEAP funds were seriously depleted around the country. In fact, I have introduced a bill with several other Members to ask for an emergency, supplemental appropriation of $300 million to carry us through this fiscal year because the money was running out.

We had testimony at a hearing that I was a part of, before the Governmental Affairs Committee, that suggested there were going to be people in this country who were literally going to freeze as a result of the exhaustion of the LIHEAP funds and their inability to pay for their heat.

On top of all this, as you consider the budget for the next fiscal year, the administration, I think, has made a devastating error in suggesting a 25-percent cut in LIHEAP funds for fiscal year 1991. Mr. Chairman, in my opinion, there will be a direct reaction if this committee and the Congress allows that cut to go through, and it is that people will suffer, that older people, disabled people, poorer people will be forced to decide whether to eat or heat, and some will even have made that decision and still not be able to have enough money to heat themselves adequately.

So I hope and pray that the committee will, on this very basic fundamental right, play a leadership role and turn this around.

Lyme disease, finally, is something that is particularly important to us in Connecticut, because actually the disease takes its name from the town of Lyme in Connecticut, where it was first discovered. But it is now appearing in over 40 States in our country; 7,400 cases were reported in 1989 alone. A total of 21,000 cases have been reported since 1982. One of the most significant problems with this disease is that it has been hard to spot, not only by people, but by medical professionals themselves, who frequently misdiagnose it, leading to general delays in treatment and extraordinary pain and suffering.

I think we have got to do more research on Lyme disease, we have got to educate both doctors and scientists about the disease, and then, finally, educate the public to look for the telltale warnings. A tick, which is really almost microscopic, carries this disease. An individual will not know he or she has it. They will, perhaps, see a red blotch on their body and then some period of time later, will begin to experience the most painful series of symptoms.

Last year, the Congress broke through and appropriated funds to NIH to conduct research in Lyme disease. I certainly urge this committee this morning to ensure that this research program at NIH will continue. Congress also provided $2 million last year to the Centers for Disease Control for Lyme disease purposes. Only $500,000 of this money will be spent outside of the CDC for research and control activities, and it looks as if none of that money is going to be able to go for the public education that is critically needed throughout the country to protect people from this disease.

So I think that it is, again, a critical for Congress to increase funding for Lyme disease research and education, as you, within your judgment, deem it to be appropriate.

Public information, I want to stress, is critical to decreasing the number of people infected and to ensuring that those who are infected will receive the best treatment possible immediately.

PREPARED STATEMENT

Mr. Chairman, that concludes my testimony. I thank you very much. I have tremendous respect for you and the task that this committee has to perform, and I have some sense of confidence in a time of limited resources, with you there, you will do the best you possibly can for critical programs, such as the ones I have mentioned.

[The statement follows:]

STATEMENT OF SENATOR JOSEPH I. LIEBERMAN

Mr. Chairman, members of the subcommittee, I am pleased to be here today to testify in support of three very important programs, Impact Aid, the Low Income Home Energy Assistance Program, and funding for Lyme disease research and education.

IMPACT AID

The Impact Aid program provides critical federal funds to those school districts which serve children whose parents live and/or work on Federal property. Communities with large numbers of federally connected children do not receive local taxes from those families to support education. The communities must rely, instead, on federal funds to replace these local taxes and to ensure that all the children in the district are given a quality education.

In Groton, Connecticut 46.3 percent of the students are federally connected. These students, who often arrive during the school year, need special services to facilitate their adjustment to a new school and a new community. The Groton school system provides excellent services to these students, but these programs cost money. This year the shortfall per Federal student is $1,621. The taxpayers of Groton must makeup this shortfall. Every year as the number of impact aid students grows and the cost of education increases, a bigger and bigger burden is placed on the taxpayers of Groton to ensure that the federally connected students receive a quality education.

As a nation we have a duty to ensure that the children of military families receive quality educations and that local school districts do not go broke trying to provide them quality educations. I urge the subcommittee to provide the Impact Aid program with adequate funds in fiscal 1991 and to ensure that each school district receives funding for every federally connected child in their classrooms.

LOW INCOME HOME ENERGY ASSISTANCE

The Low Income Home Energy Assistance Program is a lifeline for hundreds of thousands of families nationwide, 70,000 in Connecticut alone, who receive help paying their heating bills. The importance of this program was vividly illustrated this past December when recording breaking cold weather hit the northeast and midwest and people relied on LIHEAP funds to keep them from freezing. This winter also illustrated how important it is to fund the LIHEAP program adequately. Many States found their LIHEAP funds severely depleted by the end of December, and, in some areas, recipients found themselves faced with a choice of feeding their families or heating their homes. What will happen next year if we have a serious cold spell with even fewer funds available?

The subcommittee must reject the President's proposed 25-percent reduction in LIHEAP funds for fiscal 1991. Instead, the subcommittee should increase the funding over and above what was provided in fiscal 1990 to ensure that no one in the United States will freeze next winter because the Federal Government failed to provide sufficient assistance to enable them to pay their heating bills.

LYME DISEASE

Lyme disease, a vector-borne disease, continues to spread throughout the United States. In 1989 alone, 7,400 cases were reported. A total of 21,000 cases have been reported since 1982. Despite the increasing number of cases doctors often misdiagnose Lyme disease leading to dangerous delays before it is treated and the general public often does not know the importance of personal protection which can prevent the disease.

In order to combat Lyme disease we must do epidemiological research, we must educate our scientists and doctors about this disease, and we must educate the public on the importance of preventative measures. Last year Congress appropriated funds for NIH to conduct research, I urge the Subcommittee to ensure that Lyme disease research at NIH can continue. The Congress also provided $2 million to CDC. Only $500,000 of this money will be spent outside the CDC for research and control activities and, it looks as if, none of that money will go for the public education that is needed throughout the country.

I believe that Congress must increase funding for Lyme disease this year to ensure that we continue to make progress with research that will enable us first to accurately and quickly diagnose the disease and, then, to prevent it. More importantly, I think more money must be set aside to be distributed to groups around the country which can provide the education necessary to teach Americans how to prevent the disease and what to do if one is stricken by it. Public information is critical to decrease the number of people infected and to ensure that those who are infected receive proper treatment immediately.

I thank the Committee for allowing me to testify on these issues.

SUPPLEMENTAL FOR LIHEAP

Senator **ADAMS**. Thank you very much. We understand there will be a supplemental for LIHEAP, and we in the Senate—at least this Senator—will also recommend supplemental funding, so we will do what we can with that. And we included money for Lyme disease last time. We hope to do so this time, also. I know it is critical, and I appreciate the testimony you have given us this morning.

Senator **LIEBERMAN**. Thank you for your encouraging response.

Senator **ADAMS**. Thank you very much, Senator.

STATEMENT OF WILLIAM L. WINTERS, JR., PRESIDENT, AMERICAN COLLEGE OF CARDIOLOGY

Senator **ADAMS**. Our next witness is Dr. William L. Winters, Jr., American College of Cardiology.

Dr. Winters.

Dr. **WINTERS**. Good morning, Mr. Chairman. I am Dr. William L. Winters, Jr., a clinical professor of medicine at Baylor College of Medicine in Houston, TX, and a practicing cardiologist for over three decades. I am very pleased to be with you this morning as president of the American College of Cardiology.

The college is an 18,000-member, nonprofit, professional society and teaching institution, whose primary mission is to foster optimal, cardiovascular care and disease prevention.

Senator Adams, one-half of all deaths in this country are attributable to heart and vascular diseases. Because of the frequency of premature cardiovascular death, we strongly support medical research for the prevention, diagnosis, and treatment of cardiovascular disease.

The National Heart, Lung, and Blood Institute is critical in sustaining that effort. It is the centerfold, if you will, to our research and prevention message to America. Regrettably, because of current fiscal restraints, most proposals for deserving cardiovascular research, go unfunded. The societal benefits of research, including a proven reduction in deaths and disability, justify a larger public commitment to the NHLBI than is being proposed in the administration's budget.

Consequently, the American College of Cardiology urges this subcommittee to commit funding for the NHLBI at the highest reasonable level for fiscal year 1991.

While the written testimony, already submitted from our college, provides details on many facets of the institute, I will focus my remarks on three specific issues. The first, specialized centers of research, known as SCOR's; second, research projects; and third, supporting the next generation of medical researchers.

Specialized centers of research are multidisciplinary, specialized centers of research that provide the most efficient means of rapidly translating advances in basic science into clinical applications. These research centers need support to fund critical, new initiatives, as well as to maintain current programs. Yet the President's proposed budget would actually allocate less for the centers' program than was available in 1987.

Additional money is needed to provide full funding of existing specialized centers of research and to support three new proposed programs in vascular biology, sudden cardiac death, and heart failure. Specifically, sudden cardiac death is important. The incidence of cardiovascular disease and deaths overall is declining, but the incidence of sudden death has not declined.

Research project grants, let me also point your attention to the research project grant, which remains the cornerstone of the NIH's effort to advance our knowledge of the cause and cure of disease. There has been a dramatic decline in the number of new and competing research project grants, from a total of 966 in 1987 to an estimated 718 under the administration's proposal for next year. These reductions mean a lack of support for young scientists and the inability to sustain new research opportunities.

Finally, Mr. Chairman, research training programs are crucial to the mission of the NHLBI, to assure an adequate number of well-trained researchers for the next generation. While cardiology directors around the Nation overwhelmingly agree that additional researchers are needed, the President's budget provides almost no additional funding and continues the freeze on the number of trainees in effect since 1987.

Given the rapid pace of technological process, how can we afford to under fund tomorrow's innovators. Among the many other promising, new research initiatives at the NHLBI, are programs in gene therapy, coronary heart disease, prevention in high risk hypertensives and the expanded bone marrow transplantation projects.

I call your attention to an article in the New England Journal of Medicine, which I received yesterday in the mail, entitled "Declining American Representation in Leading, Clinical Research Journals," indicating a rise in non-United States papers of two to three-fold, originating mostly from Western European or Japanese sources over the past decade. And although the explanation is not clear, it coincides with the slow growth of funding for NIH clinical research.

PREPARED STATEMENT

I know your job is not an easy one and you are called upon to make difficult choices about increasingly limited Federal funds for these important programs, so on behalf of my colleagues, I thank the members of this subcommittee for your consistent support of the NHLBI, and request your continued help with our efforts to restrain the Nation's No. 1 killer, cardiovascular disease.

Thank you.

[The statement follows:]

STATEMENT OF WILLIAM L. WINTERS, JR., M.D.

INTRODUCTION

Mr. Chairman, and members of the Subcommittee, I am William L. Winters, Jr., Clinical Professor of Medicine at Baylor College of Medicine and a practicing cardiologist from Houston, Texas. I am very pleased to be with you today representing the American College of Cardiology, of which I am currently President. The College is a 17,900 member non-profit professional medical society and teaching institution whose mission is to foster optimal cardiovascular care and disease prevention through professional education, promotion of research, and leadership in the development of standards and formulation of health care policy.

SUPPORT FOR THE NATIONAL HEART, LUNG, AND BLOOD INSTITUTE

We wish to confirm our strong and ongoing support for quality medical research in the areas of prevention, diagnosis, and treatment of cardiovascular disease. The National Heart, Lung, and Blood Institute (NHLBI) is critical in sustaining that effort and we urge the Subcommittee to commit funding to the Institute at the highest reasonable level for fiscal year 1991.

The NHLBI has estimated that at least 58 million Americans suffer from the consequences of heart disease, and of these, approximately 40 million are under 65 years of age. Almost half of all deaths in this country are a result of cardiovascular disease, with the economic cost to the nation reaching $135.8 billion annually, half due to health expenditures and half attributable to lost productivity due to death and disability.

The United States has been at the forefront of cardiovascular research, which has had important societal benefits including reducing the number of heart attacks and deaths from cardiovascular disease. The programs of the NHLBI have been central to achieving these results. We applaud this Subcommittee's ongoing commitment to adequate funding of the NHLBI which has afforded our citizens the benefit of longer, more productive lives.

Fiscal constraint, however, has put the United States in danger of losing many important research projects, a cadre of future researchers, and our competitive advantage in international research.

The Administration's budget request for fiscal year 1991 for the NHLBI is $1.113 billion, an increase of only 3.7 percent over fiscal year 1990. The size of the President's request is of serious concern since such a modest increase will not even permit the Institute to sustain its current programs. Failing to compensate at a minimum for the cost of inflation in biomedical research will lead to curtailment of valuable cardiovascular research. Consequently, we join our colleagues in the medical research community in calling for a fiscal year 1991 appropriation level of $1.308 billion.

In the next few minutes, I would like to describe the specific needs of the NHLBI and the patient community it serves.

SPECIALIZED CENTERS OF RESEARCH

As a multi-disciplinary program targeted to specific disorders, the Specialized Centers of Research program (referred to as SCOR) was instituted in 1970 to advance basic knowledge and to discover the most effective techniques of clinical management and prevention in such areas as arteriosclerosis, hypertension, and ischemic heart disease. These centers provide the most efficient means of rapidly translating advances in basic science into clinical applications. There are currently 64 SCOR's in operation with some 1,200 scientists receiving support.

Three new promising areas for expansion of the SCOR programs include (1) vascular biology and medicine, (2) sudden cardiac death, and (3) heart failure. However, the Administration proposal for no effective increase in the budget for research centers would not only stifle these critical new research initiatives, but would also mean a reduction of approximately 25 percent below the recommended award to each existing center. Although fiscal constraints have forced reductions below recommended award levels in the past, researchers will be unable to effectively conduct their investigations when forced to reduce their center budgets by 25 percent.

In spite of the need to fully fund ongoing efforts and to undertake the congressional mandate for two additional SCOR's, one in cystic fibrosis and another in sleep disorders, the President's proposed budget for the program would allocate less for each of the centers program than was available in fiscal year 1987. We ask for an additional $37.8 million to provide full funding of existing Specialized Centers of Research and a realistic increase in funding to take advantage of the benefits that we foresee from the three proposed new programs in cardiovascular research described above.

RESEARCH PROJECT GRANTS

As the Subcommittee is well aware, the Research Project Grant (RPG) remains the cornerstone of the overall effort by the National Institutes of Health to advance our knowledge of the cause and cure of disease. Regrettably, the NHLBI continues to experience a dramatic reduction in its capacity to support new competing grants.

The percentage of meritorious new research proposals being supported has steadily declined from the 40th percentile in 1984 to an estimated 22nd percentile this year. In absolute numbers, the NHLBI awarded 966 new and competing RPG's in 1987, but will only be able to afford to fund 718 in fiscal year 1991 under the Administration's proposal. In addition, grant recipients are expected to experience cuts of 13 to 17 percent below their full costs of conducting the research. These reductions in the number of grants and the size of the awards are leading to growing frustration over the lack of support for young scientists and new research opportunities.

We think Congress should go beyond the Administration request in this regard and provide at least $845 million for competing and noncompeting RPG's. This would allow full funding of noncompeting grants and would allow the award of approximately 900 new grants, still below the 1987 level, but an improvement over the last three years. Even at the higher funding level, fewer than one-third of approved competing grants would be funded.

TRAINING PROGRAMS AND RESEARCH CAREER AWARDS

A recent survey of cardiology training directors by the American College of Cardiology revealed overwhelming agreement among directors that additional researchers are needed in our field. Physician researchers contribute clinical relevance to research and are therefore critically important to the success of transferring basic research to the patient's bedside.

The President's proposed budget would provide $44.5 million for research training programs, essentially the same amount of funding as in fiscal year 1990 and a continuation of the freeze on the number of trainees that has been imposed since fiscal year 1987. This vital effort should receive, at a minimum, an increase to account for the cost of inflation in order to provide needed funding stability.

In addition to training, the Research Career Awards are crucial to the mission of the NHLBI to assure an adequate number of well-trained researchers for the next generation. The Administration's proposal would freeze the budget and the number of awards currently provided, and we believe that this shortsighted approach would jeopardize future research manpower needs. The need for training and specialized research experience for our future investigators is often overlooked, yet may indeed be the most important facet of our biomedical research effort. Given the rapid pace or technological innovations in the area of cardiovascular science, we cannot afford to underfund tomorrow's innovators.

OTHER SIGNIFICANT INITIATIVES

Among the other promising new cardiovascular research initiatives at the NHLBI are programs in gene therapy and coronary heart disease prevention in high risk hypertensives. In addition to these cardiovascular programs, the Institute will require additional funding for its programs of lung and blood research, including programs such as the expanded bone marrow transplantation projects, which can lead to breakthroughs which have applications for heart and vascular disease.

Moreover, with congressional support for its highly effective education programs, the Institute is able to apply the results of research to visible improvements in public health through prevention. These public education efforts include the National High Blood Pressure Education Program, the National Cholesterol Education Program, and the NHLBI Smoking Education Program, all of which have successfully helped millions modify unhealthy habits by training physicians and allied health professionals to serve as intervenors.

NATIONAL LIBRARY OF MEDICINE

The American College of Cardiology also takes this opportunity to voice continued strong support for the work of the National Library of Medicine. The College and those who participate in our educational programs benefit directly from the outstanding resources of the Library.

SUMMARY AND CLOSING REMARKS

In summary, I want to stress the critical importance of cardiovascular research and the contributions of National Heart, Lung, and Blood Institute. Cardiovascular disease is the major cause of death in Americans and causes tremendous personal and economic loss to the citizens of this nation. We at the American College of Cardiology want to emphasize our support for funding at the highest reasonable level for Specialized Centers of Research, Research Project Grants, Training Programs, and Research Career Awards. We believe that these programs are vital to the continued development of research in cardiovascular disease.

Mr. Chairman, I appreciate the opportunity to appear before this distinguished Subcommittee today. On behalf of my colleagues in cardiovascular medicine, I wish to thank the members of the Subcommittee for your consistent support of the NHLBI and your help with our efforts to restrain the nation's number one killer—heart disease.

BIOMEDICAL FIELD

Senator **Adams**. Thank you, Dr. Winters. One of the questions that has faced the committee and which has concerned us in a number of fields, but we are particularly concerned in the biomedical field and the other biotechnical fields connected with it, is the amount of funding necessary to accelerate the pace of transfer of new knowledge, in other words, basic research, into education and prevention programs. These seem to be the key or the answer, at least, to a great many of the cardiovascular problems that we have, ranging all the way from smoking, cholesterol, and so on.

Do you have any recommendations on funding or programmatic changes in that field because I think that is what you mentioned specifically, was that the Japanese and Germans seem to be doing this at a more rapid and more organized pace.

Dr. **Winters**. Well, the consensus of those that I have talked to is that the SCOR program, the specialized centers of research, which combine basic science and clinical research under the same multidisciplinary roof, if you will, seems to be the best way that we have of transferring that information from the basic science to clinical research and to clinical practice. In Houston at Baylor, we have several SCOR programs. The most recent one, under the topic of the treatment of congestive heart failure, has been very useful in aligning the basic researchers and the clinical researchers together, and I think that is where funding will be most useful.

Senator **Adams**. Thank you, Doctor. Your testimony has been very helpful, and we appreciate your being here this morning.

STATEMENT OF GERALD L. VAN HOOSIER, PROFESSOR AND CHAIRMAN, DEPARTMENT OF COMPARATIVE MEDICINE, UNIVERSITY OF WASHINGTON

Senator ADAMS. Next, we call on Dr. Gerald L. Van Hoosier, Jr., professor and chairman, Department of Comparative Medicine, University of Washington.

Doctor, welcome. You teach at my alma mater, and I am very pleased to welcome you here this morning, and look forward very much, to hearing your testimony.

Dr. VAN HOOSIER. Thank you, Senator Adams, and I appreciate your time and the assistance of the staff members of the subcommittee. By way of introduction, I am a veterinarian with specialty certification in laboratory animal medicine. My experience over the past 30 years include 5 years in the National Institutes of Health, 6 years at Baylor College of Medicine, and 20 years with either the veterinarian school at Washington State University or the medical school at the University of Washington. In addition to chairing the department of comparative medicine, I am also the attending veterinarian for the university.

I am representing a group of concerned laboratory animal scientists. We are advocating a revitalization of the national laboratory animal research infrastructure.

Senator Adams, as you know well, medical progress depends on research, and approximately 50 percent of the biomedical research today uses experimental animals. Unfortunately, during the past decade, we have witnessed an erosion rather than an advancement of the National Laboratory and Animal Research Program. This erosion has occurred at a time when the demands on laboratory animal units, such as ours, both the personnel and resources. have increased exponentially, in association with the proliferation of regulatory responsibilities and the intense public scrutiny of animal-related research.

I would like to summarize three major issues and mention several recommendations which we submitted in complete form for the record.

The health and welfare of animals in research must be protected to assure reliable research results, prevent pain and distress and provide the psychological well-being of research animals. Strong research programs in laboratory animal medicine must be provided at the National Institutes of Health grantee institutions to further improve the health and well-being of laboratory animals and the quality of animal-related research.

One-half of all NIH-supported extramural research requires the use of animals, but NIH spends less than 0.5 percent of its extramural animal research budget on programs for professional management of research animals.

Additional veterinarians who specialize in clinical and research training are required to assure the health and welfare of the Nation's research animals and maintain public trust in animal experimentation. National funding for such training must be provided.

The recommendations include that we double the number of investigator-initiated research projects addressing problems in the health and welfare of laboratory animals and that we establish three comprehensive centers of excellence to accelerate research on problems with laboratory animals and provide high-quality programs for advanced research training of laboratory animal scientists.

We also recommend that we fund all 75 authorized national research service award training positions for laboratory animal veterinarians.

PREPARED STATEMENT

In conclusion, Congress is urged to increase appropriations to the laboratory animal scientist program of the extramural research resources to the national center of research resources at the National Institutes of Health from its current level of approximately $10 million to a new level of approximately $20 million annually.

Thank you, Senator Adams.

Senator ADAMS. Thank you very much, Doctor, for your interesting and informative testimony. The committee appreciates it and without objection, your entire statement will appear as though given.

Dr. VAN HOOSIER. Thank you.

[The statement follows:]

STATEMENT OF GERALD L. VAN HOOSIER, JR.

SUMMARY

The use of animals in biomedical research is essential to combat disease. Spectacular advances have been made through animal research in discovering causes and treatments for heart disease, diabetes, infectious diseases (including AIDS), kidney diseases, eye diseases, diseases of aging and scores of other conditions. A recent report of the National Research Council concludes that research using animals is essential to the nation's health needs and that the vast majority of Americans support the appropriate and humane use of animals in biomedical research.

ISSUES

The health and welfare of animals used in research must be protected to assure reliable research results, prevent pain and distress, and provide for the psychological well-being of research animals.

Strong research programs in laboratory animal medicine must be provided at NIH grantee institutions to further improve the health and well-being of laboratory animals and the quality of animal-related research. Half of all NIH supported extramural research requires the use of animals, but NIH spends less than 0.4 percent of its extramural animal research budget on programs for professional management of research animals.

Additional veterinarians with specialized clinical and research training are required to assure the health and welfare of the nation's research animals and maintain public trust in animals experimentation. National funding for such training must be provided.

RECOMMENDATIONS

Double the number of investigator initiated research projects addressing problems on the health and welfare of laboratory animals from (22 to 44).

Strengthen existing Animal Resource Laboratories by updating equipment and stabilizing funding. In addition, establish three new Animal Resource Laboratories at research institutions that lack such resources.

Establish three Comprehensive Centers of Excellence to accelerate research on problems of laboratory animals and provide high quality programs for advanced research training of laboratory animal scientists.

Fund all 75 authorized National Research Service Award training positions for laboratory animal veterinarians.

Expand advanced training opportunities for laboratory animal veterinarians through Special Emphasis Research Career Awards, Clinical Associates Programs, and Senior Fellowships.

Increase efforts to attract veterinarians into laboratory animal medicine by expanding the Summer Research Fellowship Program for veterinary students.

ISSUES AND RECOMMENDATIONS

The recent report of the National Research Council (NRC) entitled "Use of Laboratory Animals in Biomedical and Behavioral Research", emphasized advances in biology and medicine made possible through animal research. Unprecedented progress has been made in the alleviation of human and animal suffering as a direct result of research using animals. Many breakthroughs are well known, such as the discovery of insulin and the development of vaccines that prevent infection. Spectacular advances have been achieved in organ transplantation and the development of artificial heart valves, ocular lenses, blood vessels and joints. Animal studies also have made possible the development of drugs to treat AIDS, behavioral disorders, chronic pain, high blood pressure, gastric ulcers and scores of other illnesses, thus extending and enhancing the quality of life. There is agreement in the scientific community that animal studies continue to play a vital role in research on the fundamental processes of life and are essential for pursuit of cures for chronic diseases such as arthritis, osteoporosis, multiple sclerosis, muscular dystrophy, Alzheimer's disease and numerous other currently incurable human diseases.

The NRC report concluded that animal-related research must continue and that the vast majority of Americans support the appropriate and humane use of animals in research.

Issue 1. The health and welfare of animals used in research must be protected to assure reliable results, prevent pain and distress, and provide for the psychological well-being of research animals.

Advances in laboratory animal science during the past quarter century have significantly improved the quality of animals used in research, but the threat to research from detrimental variables remains unacceptably high. Costly, sophisticated studies can be comprised or distorted by infectious, environmental and nutritional factors. In the proceedings of a recent NIH-sponsored symposium entitled "Viral and Mycoplasmal Infections of Laboratory Rodents: Effect on Biomedical Research", a distinguished group of scientists voiced concern about the impact of intercurrent infections of laboratory animals on the outcome of research. Additional effort is needed to clarify the effect of infections on research animals and improve measures for protecting animals from these confounding influences.

Environmental stimuli (light, diet, temperature, animal bedding, etc.) and nutritional factors affect biological responses and the longevity of laboratory animals. For example, even minor changes in animal care and housing can alter immune responses, drug metabolism and reproductive patterns, which may lead to erroneous results or to a need for additional animals to verify the cause of altered responses. Research productivity can be increased and the number of animals used in research decreased if effects of environmental and nutritional factors are understood and controlled.

Improvement of the psychological well-being of animals used in research is a worthy goal. There is, however, little reliable data concerning the psychological effects of standard laboratory animal care and housing. Furthermore, there are virtually no data on which to predict whether the well-being of laboratory animals will improve if changes in animal housing and care proposed by amendments to the Animal Welfare Act are enacted at a cost that could exceed $1 billion. Additional research must be conducted to design and evaluate psycho-social environments that optimize animal health and psychologic well-being without compromising the research for which the animals are used.

Scientists have a responsibility to select research methods that minimize pain and distress to animals and that minimize animal use. Additional research must be done to meet this responsibility. New methods that have the potential to alleviate pain need to be developed and reliable alternatives to the use of animals need to be explored. Currently, such research is poorly funded. Revitalization of the animal research infrastructure would assure progress toward reducing the ethical confrontations associated with animal research.

Issue 2. Stronger research programs in laboratory animal medicine are needed at NIH grantee institutions to further improve the health and well-being of research animals and the efficiency of research using animals.

About half of all research programs funded by NIH use animals. To assure that this large investment is protected, grantee institutions must provide high quality animal care. In additional to assuring humane care, laboratory animal resource programs should be staffed and equipped to investigate and solve problems affecting the use of animals in research. Pressing problems include a need for better understanding and control of environmental variables that can interfere with research, improvement of methods to detect and control infectious diseases, improvement of methods for minimizing and eliminating pain and distress, and improvement of the psychological well-being of animals. In addition, discovery and development of new animal models for human disease is essential.

Unfortunately, the past decade has witnessed an erosion rather than advancement of the nation's laboratory animal resource programs. Regulatory responsibilities of laboratory animal veterinarians have proliferated and animal-related research has come under intense public scrutiny. These conditions have placed overwhelming demands on the relatively few veterinarians trained in laboratory animal medicine and diminished their opportunities for research on the very issues that contribute to public controversy.

Another major factor eroding institutional animal resource programs is the shrinking budget of the NIH's Laboratory Animal Sciences Program (LASP). The LASP is the part of the Division of Research Resources of NIH that supports research and training activities relevant to laboratory animals. The LASP budget presently is about $10 million, which is less than 0.4 percent of the annual budget for biomedical research using animals supported by NIH. Currently only 22 research grants are funded nationwide by the LASP, and only 7 of these pertain to laboratory rodents and rabbits, despite the fact that these species constitute 95 percent of animals used in research. We recommend that this number be doubled to 44 grants, to provide an adequate research base to study problems in laboratory care medicine.

The NIH sponsors only 16 Animal Resource Laboratories that provide support for optimal veterinary care at more than —— grantee institutions. Many of these laboratories are 15 to 20 years old and lack modern instrumentation essential to service, research and training. Existing laboratories must be modernized and at least 3 new laboratories should be added at major institutions using animals for research. In addition, 3 existing Animal Resource Laboratories should be designated as Comprehensive Centers of Excellence. Comprehensive Centers would be eligible for additional funding for 5 to 7 years per award to pursue research in greater depth than incurrently feasible because of limitations in NIH programs. The Centers would also provide advanced research training for veterinarians who have qualified as laboratory animal specialists. This need is also addressed in the next section.

Issue 3. Additional veterinarians with specialized clinical and research training are required to meet the needs of the nation's research animals and to maintain public trust in animal studies.

Since the late 1960's Federal, state, and local governments have enacted numerous laws and developed high standards affecting the care and use of laboratory animals. Many research institutions are struggling to comply with these standards because of insufficient funding to renovate animal care facilities and a shortage of laboratory animal veterinarians. Governmental agencies charged with regulating animal care and use also are frequently unable to recruit veterinarians trained in laboratory animal medicine. For example, veterinarians employed by the USDA to oversee compliance with the Animal Welfare Act are rarely certified by the American College of Laboratory Medicine.

Specialty training in laboratory animal medicine requires at least 2 to 3 years and training institutions must provide experienced faculty and animal facilities adequate for broad clinical exposure. Clinical experience enables laboratory animal medicine specialists to administer programs that comply with standards for animal care and advise scientists about appropriate methods of animal experimentation. Laboratory animal veterinarians also must develop greater expertise in research in order to investigate the biology and diseases of laboratory animal diseases pertinent to health research using animals.

Research training requires more programs, facilities, and faculty than are currently available. Without adequate research skills, veterinarians will not be able to provide new information to reduce the cost and numbers of animals needed in research or to improve animal welfare. The Animal Resources Branch, Division of Research Resources of NIH, has approved 75 training positions at 16 research institutions for veterinarians specializing in laboratory animal medicine and comparative medicine, but only 66 of the positions have been funded. We strongly urge finding for all 75 approved training positions for the next 5 years to help alleviate the shortage of veterinarians trained in laboratory animal medicine.

We also recommend the following approaches to strengthen advanced research training of laboratory animal medicine specialists: (a) increase the number of Special Emphasis Research Career Awards; (b) provide a Clinical Associates Program for veterinarians who wish to develop research skills in clinical areas; (c) provide Senior Fellowship awards for established laboratory animal medicine specialists to increase their productivity and expertise in research; (d) fund the aforementioned Centers of Excellence and (e) expand support for investigator initiated research.

Relatively few veterinarians select careers in laboratory animal medicine, primarily due to lack of exposure to the specialty prior to graduation. Summer fellowships for veterinary students to work at institutions with training programs in laboratory animal and comparative medicine have been effective means of addressing this deficiency. The Summer Fellowship Program in laboratory animal medicine and comparative medicine should be strengthened to attract future veterinarians to the field. To attract interested students, the pool of Summer Fellowships should be doubled.

FINANCING THIS PROPOSAL

Congress is urged to increase appropriations to the Laboratory Animal Sciences Program, Division of Research Resources of NIH from its current level of approximately $10 million to a new level of about $20 million annually as summarized in the attached budget proposal. This appropriation will ensure adequate professional management of the nation's laboratory animal research programs and maintain public confidence in biomedical research using animals. This increase of only $10 million to revitalize the infrastructure of a critical part of the nation's biomedical research enterprise, will yield enormous benefits for human health research.

REVITALIZATION OF THE NATIONAL INFRASTRUCTURE FOR LABORATORY ANIMAL RESEARCH

[Estimated costs of proposed solutions]

Recommendation	Number of awards		Estimated cost fiscal year 1991
	Current	Proposed	
Double the number of individual research grants	22	44	$3,080,000
Establish three new animal resource laboratories and reequip existing laboratories [1]	16	16	420,000
Redesignate three existing animal resources laboratories as comprehensive centers of excellence		3	2,520,000
Fund National Research Service awards in laboratory animal medicine to authorized levels	66	75	630,000
Add eight special emphasis research career awards in laboratory animal medicine	12	20	1,260,000
Create 12 clinical associates positions in laboratory animal medicine		12	840,000
Add two senior fellowship awards in laboratory animal medicine		2	168,000
Double the number of summer fellowships in laboratory animal medicine	20	40	84,000
Total			9,912,000

[1] Three existing laboratories would be redesignated as comprehensive centers of excellence.

STATEMENTS OF:

THOMAS FISE, EXECUTIVE DIRECTOR, AMERICAN COLLEGE OF GASTROENTEROLOGY

JOHN T. FARRAR, PRESIDENT, DIGESTIVE DISEASE NATIONAL COALITION

THELMA KING THIEL, PRESIDENT AND CHIEF OPERATING OFFICER, AMERICAN LIVER FOUNDATION

ACCOMPANIED BY MARY ELLEN LANNIN, RECIPIENT OF LIVER TRANSPLANT

Senator ADAMS. The next group of witnesses will appear in a panel, and I want to call forward at this time, Thomas Fise, executive director of the American College of Gastroenterology; Dr. John Farrar, Medical College of Virginia, Digestive Disease National Coalition [DDNC]; and Thelma King Thiel, president of the American Liver Foundation. Welcome, all of you, and we look forward to hearing you as a panel.

Dr. FARRAR. Thank you very much. Let me start off. Mr. Chairman and members of the subcommittee, I am John Farrar, a physician in Richmond and a professor of medicine at the Medical College of Virginia. I am very pleased to appear before you to discuss Federal funding for digestive disease research. I represent both the DDNC, this coalition, as well as the American Gastroenterology Association and one of the members of the coalition.

This committee should be commended for its past support of funding for all of the NIH, as well as the NIDDK. The digestive community is in your debt for your past wisdom.

The DDNC is comprised of 22 national and medical and voluntary organizations that are concerned with various digestive diseases, and these are, many of them, serious. We will represent 110,000 members. Digestive diseases are the No. 1 cause of hospital admissions in the United States and cost Americans about $50 billion a year in health care cost and lost wages.

One of the points, DD—digestive diseases need help, but I am more concerned about the entire biomedical research enterprise. It is suffering from a lack of funding. We are way, way behind in our overall commitment and investment in basic and clinical medical research. In fact, in all research, except military research. If we compare the cost of treating diseases and illnesses against our investment in research and prevention, the results are terribly lopsided, and instead of getting better, it appears things are getting worse.

NIDDK is funding grants at less than 20 percentile. Can you imagine funding only one-fifth of good science? Bright, young scientists are being discouraged from entering biomedical research. I hate to be an alarmist, Mr. Chairman, but I want this country to continue to be the intellectual and scientific leader of the world. We cannot do it without adequate support.

The DDNC, this coalition, has several specific recommendations for your consideration. One, provide an overall funding level of $9.2 billion for the NIH. This is consistent with the recommendations made by the Ad Hoc Group for Medical Research.

Two, include $808 million for the National Institute of Diabetes and Digestive and Kidney Diseases. This will provide support for 33 percent of approved, competing research grants, 40 research centers, and 178 career development awards.

Three, continue to provide additional funding for the DD epidemiology data systems and the clearinghouse.

Four, provide additional funding for inflammatory bowel disease research per the recommendations made by the NIDDK in accord with Senator Reid's wishes of last year.

Five, support relatively new initiatives for studying medical effectiveness—and this relates to what you were saying earlier, Mr. Chairman—and treatment outcomes. This has the potential, the supplied research, to save billions of Federal health care treatment dollars that could be better spent to understand disease.

PREPARED STATEMENT

I know that you and your colleagues are under frightful, budgetary pressures. Those of us who are urging substantially increased funds are passionately interested in the health of our citizens, the excellence of our research and the stature of this country in science.

Mr. Chairman, thank you for the opportunity to present the views of the DDNC. I will be pleased to respond to any questions you may have.

Senator ADAMS. Thank you, Dr. Farrar.

[The statement follows:]

STATEMENT OF JOHN T. FARRAR, M.D.

Mr. Chairman and members of the subcommittee, I am very pleased to appear before you to discuss federal funding for Digestive Disease research.

This subcommittee should be commended for its support of funding for all of the National Institutes of Health, including the National Institute of Diabetes, and Digestive and Kidney Diseases. We particularly appreciate the special emphasis you have placed upon supporting the Digestive Disease Centers program and the additional funding that its being provided for Inflammatory Bowel Disease research. The digestive disease community is in your debt.

Mr. Chairman, the Digestive Disease National Coalition is comprised of 22 national medical and voluntary organizations that are concerned with various digestive diseases. There are over 150 major disorders of the digestive system alone. Digestive diseases are the number one cause of hospital admissions in the U.S. and cost Americans about $50 billion each year in health care cost, lost wages, and other variables.

These are not just upset stomach and gas but very serious conditions such as hepatitis, ulcers, gallbladder disease and inflammatory bowel disease. Although digestive diseases are very important, and this is the field in which I am expert, the more important point is that all biomedical research is suffering.

We are way, way behind in our overall commitment and investment in basic and clinical medical research, in fact, in all research except military research. If we compare the costs of treating diseases and illness against our investment in research and prevention, the results are terribly lopsided, and instead of getting better, it appears that things are getting worse. NIDDK is funding grants at less than the 20th percentile. Can you imagine funding only a fifth of good science? Bright young scientists are discouraged from entering biomedical research. I hate to appear to be an alarmist, but I want this country to continue to be the intellectual and scientific leader in the world. We cannot do it without adequate support for research, people and equipment.

I believe that we must fund more of the best grants by increasing the funding for NIDDK by more than the proposed 3½ percent.

The Digestive Disease National Coalition has several specific recommendations for your consideration:

(1) Provide an overall level of funding of $9.2 billion for NIH. This is consistent with recommendations made by the Ad Hoc Group for medical research.

(2) Include $808 million for the National Institute of Diabetes, and Digestive and Kidney Diseases. This will provide support of 33 percent of approved competing research grants, 40 research centers, and 178 career development awards. This was also the professional judgment figure provided by the NIDDK for their fiscal year 1991 needs.

(3) Continue to provide additional funding for the DD Epidemiology Data Systems, and the DD Information Clearinghouse.

(4) Provide additional funding for Inflammatory Bowel Disease research, per the recommendations made by NIDDK.

(5) Support relatively new initiatives to study medical effectiveness and treatment outcomes. This has a potential to save billions of federal health care treatment dollars that could be better spent to understand disease.

I know that you and your colleagues are under frightful budgetary pressures. Those of us who are urging substantially increased funds are passionately interested in the health of our citizens, the excellence of our research and the stature of this country in science.

Mr. Chairman, thank you for the opportunity to present the views of the Digestive Disease National Coalition. I am pleased to respond to any questions you may have.

STATEMENT OF THELMA THIEL

Dr. **Farrar**. Next, I would like to introduce Thelma King Thiel. Thelma.

Senator **Adams**. Dr. Thiel, we are pleased to receive your testimony.

[The statement follows:]

Statement of Thelma King Thiel

Good morning, Mr. Chairman and members of the subcommittee, I am Thelma King Thiel, President and Chief Operating Officer of the American Liver Foundation and Chairman of the Digestive Disease National Coalition. We are all here today for two major reasons: to reduce the human suffering caused by digestive diseases and to reduce health care costs.

We also know that research is the only way we are going to accomplish this goal. I remember back to my nursing school days when I spent hours putting hot packs on patients with polio trying to reduce their muscle spasms. It wasn't until research discovered the polio vaccine that the pain, suffering and tremendous cost of treating polio victims was eradicated. This year another miraculous research breakthrough occurred in the identification of the Hepatitis C virus and the development of a screening test. This test will drastically reduce the incidence of this blood borne disease that has threatened everyone who has needed a blood transfusion. FK506, a new and greatly improved immunosuppressant drug, discovered in Japan, and now being tested here in the United States, is showing great promise in reducing postoperative complications in liver transplant recipients.

Patients with gallstones, who were very ill and poor risks for gallstone surgery, now have hope for survival with the use of ursodeoxycholic acid, a medication that dissolves gallstones. This same drug is currently being tested in the treatment of patients with primary biliary cirrhosis and sclerosing cholangitis. Preliminary findings show promise that this medical treatment could become a treatment of choice, replacing the need for liver transplants. The outcome depends on researchers' clinical investigation.

Mary Ellen Lannin, sitting here beside me, was a victim of sclerosing cholangitis. Her only hope for survival was a liver transplant. That medical miracle was performed in January, 1989. She and her husband are now working with the American Liver Foundation, as volunteers, to raise funds to encourage young scientists to enter the field of liver research. We need more miracles like Mary Ellen. But we need many researchers to make sure these miracles continue * * * for without sufficient funding to support the work of these talented, highly trained men and women, life saving research advances will be curtailed, researchers will be lost to private practice, and costs for caring for patients with incurable diseases will continue to escalate.

Research is an investment we can't afford to cut.

We are all aware of the remarkable progress being made in discovering new treatments for AIDS patients. Victims of liver diseases wait anxiously in the wings, praying that you will consider their plight when you're setting your priorities.

Thank you for giving me this opportunity to share our concerns with you.

SUMMARY STATEMENT

Dr. **Thiel**. Good morning, Senator Adams. I am Thelma King Thiel, president and chief operating officer of the American Liver Foundation and chairman of the Digestive Disease National Coalition.

We are here today for two major reasons: to reduce the human suffering caused by digestive diseases and to reduce health care costs. We also know that research is the only way we are going to accomplish this goal.

I remember back to my nursing school days when I spent hours putting hot packs on patients with polio, trying to reduce their muscle spasms. It wasn't until research discovered the polio vaccine that the pain, suffering and tremendous cost of treating polio victims was eradicated. This year, another medical research breakthrough occurred in the identification of the hepatitis C virus and the development of the screening test. This test will drastically reduce the incidence of this blood-borne disease that has threatened everyone who has needed a blood transfusion.

FK506, a new and greatly improved immunosuppressant drug, discovered in Japan, by the way, and now being tested here in the United States, is showing great promise in reducing postoperative complications of liver transplant recipients. Patients with gallstones, who were very ill and poor risks for gallstone surgery, now have hope for survival with the use of ursodeoxycholic acid, a medication that dissolves gallstones. This same drug is currently being tested in the treatment of patients with primary biliary cirrhosis and sclerosing cholangitis. Preliminary findings show promise that this medical treatment could become a treatment of choice, replacing the need for liver transplants. The outcome depends on researchers' clinical investigation.

Mary Ellen Lannin, sitting here beside me, was a victim of sclerosing cholangitis, a fatal liver disease. Her only hope for survival was a liver transplant. That medical miracle was performed in January 1989. Both she and her husband are now working with the American Liver Foundation, as volunteers, to raise funds for research, to encourage young scientists to enter the field of liver research.

We need more miracles like Mary Ellen, but we need many more researchers to make sure that these miracles continue, for without sufficient funding to support the work of these talented, highly trained men and women, life-saving research advances will be curtailed, researchers will be lost to private practice and the cost of caring for patients with incurable liver diseases will continue to escalate.

Research and investment, we can't afford to cut. We are all aware of the remarkable progress being made in the discovery of new treatments for AIDS patients. Victims of liver diseases wait anxiously in the wings, praying that you will consider their plight when you're setting your priorities.

Thank you for giving me this opportunity to share our concerns with you.

Senator ADAMS. Thank you very much, Dr. Thiel.

STATEMENT OF THOMAS F. FISE

Senator ADAMS. The last member of our panel, Mr. Tom Fise.

Dr. FISE. Thank you, Senator. I have a statement that I would hope could be entered into the record and simply make some abbreviated comments.

Senator ADAMS. Without objection, the entire statement will appear in the record as though given.

Dr. FISE. Senator, my name is Thomas F. Fise, and I am executive director of the American College of Gastroenterology. The college is a physician organization representing gastroenterologists and gastrointestinal specialists. Our members are generally the physicians who spend the largest portion of their time in the direct care of patients with digestive diseases.

Dr. Farrar has indicated very well the economic losses that are attributed to these diseases. Our members see, on a daily basis, the heart-rending, personal losses and distresses that these conditions ravage upon the patients whom they treat.

We want to commend this committee for its past support of funding for research on digestive diseases. At the same time, we want to underline the fact that to really make a difference in this area, we need a very broad capacity for increased new research across a broad spectrum of GI diseases. We need to increase the capacity for the NIDDK to fund research, beyond the 3.5-percent increase currently contemplated. We need to up the percentile ranking of that research, which achieves funding, from the current 20 percent to something in the range of one-third or 33 percentile.

We endorse the recommendation of the Digestive Disease National Coalition, that the funding level for the NIDDK be set at $808 million. We also want to encourage the enhanced commitment to funding research for inflammatory bowel disease.

In conclusion, we also want to encourage the committee to provide funding for research on medical effectiveness and patient outcome, and we would like to use an example that relates to the delicate interrelationship in our current environment between Federal commitments for research, health cost containment initiatives and appropriate use of technology.

As an example, we would like to use the colorectal cancer rates, which currently are a No. 2 killer in this country. Presently, our best means of approaching this condition is diagnostic and therapeutic colonoscopy. Unfortunately, in the waning hours of the last Congress, in order to meet the Gramm-Rudman targets, instead of being a priority, colonoscopy was slated for across-the-board cuts in the range of 10 percent, and unfortunately, the administration's 1991 budget proposes to go back and cut this procedure once again. This is not within the direct purview of this committee, but nonetheless, good, medical research must work hand in hand with making use of the best technology currently available.

PREPARED STATEMENT

In conclusion, we need your support for new and better therapies for colorectal cancer and countless other digestive diseases by increasing your 1991 commitment of funds to the National Institute of Diabetes, Digestive Diseases and Kidney Diseases, but we also need your understanding and forbearance from false economies, and we need a realistic approach to patient outcomes and medical effectiveness so that we can make the most of the technologies that we do have available.

We thank you for your support and understanding and appreciate the opportunity to visit with you.

[The statement follows:]

STATEMENT OF THOMAS F. FISE

My name is Thomas F. Fise, and I am the Executive Director of the American College of Gastroenterology, We are pleased to have the opportunity to present testimony with respect to 1991 appropriations for the National Institutes of Health, and more specifically for the National Institute of Diabetes, and Digestive and Kidney Diseases.

Introduction

The American College of Gastroenterology is a physician organization representing gastroenterologists and other gastrointestinal specialists. Founded in 1935, the College currently has 3,418 physicians among its membership. While the majority of these physicians are gastroenterologists, the College's membership also includes surgeons, pathologists, radiologists, hepatologists, and other specialists in various aspects of the overall treatment of digestive diseases and conditions. The College has chosen to focus its activities on clinical gastroenterology--the issues confronting the gastrointestinal specialist in treatment of patients with digestive diseases.

Because our members are generally physicians who spend the largest portion of their time in direct care for patients, we are uniquely interested and concerned that every effort toward new advancements in treatment and patient care be explored and encouraged. We join Dr. Farrar in commending this Committee for its past support in making funds available for research on gastrointestinal diseases; we also join, however, in attesting that much more needs to be done.

The College is one of the 22 national organizations that comprise the Digestive Disease National Coalition. Dr. Farrar's testimony underlines the range of digestive disorders and the tremendous financial losses in cost of care and lost wages that are generated because of these conditions. We want to underline, as well, the heart-rending personal losses and distress that these conditions ravage upon the patients whom our members treat. The personal trials, chronic pain and discomforts and limitations in quality of life--both from the social and employment standpoints--which these patients endure are beyond being reduced to financial terms.

We urge this Committee to acknowledge the quiet, courageous struggles of these patients--many within your own districts and constituencies--and make a significant commitment to the biomedical research needed to wipe out these conditions, or to improve treatments in a way that holds promise for these patients. To really make a difference, we need a broad capacity for increased new research across a broad spectrum of GI diseases--to do so definitely will require a funding increase to NIDDK in excess of the 3-1/2% currently contemplated. We want to reiterate the DDNC's testimony that increases to allow funding at least up to the 33rd percentile is essential. We endorse the $808 million funding for NIDDK requested by the DDNC, and underscore the need for the Committee to follow through on the enhanced commitment to funding research on inflammatory bowel disease.

In conclusion, we want to encourage the Committee to provide funding for research on medical effectiveness and patient outcomes by using an example that relates to the delicate interrelationship of federal commitments to research funding, health cost containment and appropriate usage of technology. Colorectal cancer is our #2 cancer killer--both nationally, and on a state-by-state basis in most states. For example, in Iowa 850 citizens died from this disease in 1988, and an additional 2100 new cases were diagnosed. At present, our best tool in reversing that trend is diagnostic and therapeutic colonoscopy. However, an unfortunate thing happened in the waning hours of the last Congress--instead of being a priority, colonoscopy was slated for an across-the-board cut in the range of 10%. To make matters worse, the administration's 1991 budget proposes to go back to this procedure again for another cut this year in the same order of magnitude. We need your help to fund new research on this deadly killer; and we also need to have Congress not create addditional disincentives for physicians to use the best tool that we currently have available in our arsenal to fight this deadly disease.

Health cost containment is everybody's business, and physicians are doing their part. We recently received a report on a survey on physician time which indicates that up to one-third of a physician's time is spent on activities from which over 60 percent of physicians derive absolutely no revenue whatsoever through billings, and this does not include uncompensated care which routinely may run as high as 20-25% Budget cutters now raise questions about whether too many colonoscopy procedures are being done; that utlization guidelines are needed to save federal dollars and to assure that these procedures are done only when medically necessary. The College has worked with other GI societies in developing a proposal that would recommend that federal reimbursement policy for all endoscopic procedures be contingent upon adherence to existing practice guidelines and the prerequisite of hospital credentialling for the individual performing the procedure. As physicians, our members recognize the need to control health care costs. We need for Congress and federal regulators to realize, however, how important it is to avoid false economies such as disincentives to colonoscopy, since generally, these endoscopic procedures actually save federal funds over the longer term by avoiding more wasteful alternatives. Prior to the availability of colonoscopy, the alternative treatment was surgical removal. If disincentives to colonoscopy were succcessful, the federal government could end up paying for extended hospitaliations attendant to surgery--which could have been avoided by timely colonoscopy--as well as the potentially exorbitant financial and human losses that can be associated with advanced cancers.

We need your support for new and better therapies for colorectal cancer and countless other digestive diseases by increasing your 1991 commitment of funds to the National Institute of Diabetes, and Digestive and Kidney Diseases. But we also need your understanding and forbearance from false economies, and we need a realistic approach to patient outcomes and medical effectiveness, so that we can make the most of the technologies that we do have available.

We appreciate the opportunity to present our position, and would be pleased to answer any questions, either now or for the record.

Senator **Adams**. Thank you all very much. I have a couple of questions.

Dr. Farrar, in your testimony you recommend providing additional resources for inflammatory bowel disease. Do you have a figure of the additional amount that you would recommend?

Dr. **Farrar**. The national foundation is asking for $2 million. They have submitted testimony for the record. They are not testifying this morning, but my understanding is they are asking for, I think, $2 million. Last year there was $500,000 that was earmarked for digestive disease, inflammatory bowel centers.

Senator **Adams**. Thank you, Doctor.

Dr. Thiel, I noticed you included with this viral hepatitis and you made a comment on discoveries regarding hepatitis C. Would you describe that a little bit so that I will have some idea of what should be presented to the committee with regard to that specific subject?

Dr. **Thiel**. Well, for a long time we have had what they have been calling non-A, non-B hepatitis. It was not A and it was not B, and they did not know what it was, and 85 to 90 percent of the blood transfusion hepatitis is related to this new virus that they have identified as hepatitis C.

It is my understanding that the FDA is considering approval of this new screening test that is going to make our blood supply much safer for you and me and for all those folks who are having cardiac surgery or other kinds of surgery.

You would have maybe a 5- to 10-percent risk of developing this non-A, non-B hepatitis when you receive more than one or two blood transfusions, so it is a very important breakthrough in our research.

Senator **Adams**. Thank you very much. Thank you all very much for your testimony. We appreciate it. It was excellent.

Since we have been going rather hard at this and I have, I told you, one short commitment, the committee will stand at recess for 10 minutes, but never fear, we will get through everyone and it will all be done, so the committee will be in recess for 10 minutes.

[A brief recess was taken.]

Senator **Adams**. The committee will come to order, and we understand that one of our witnesses has a transportation problem.

STATEMENT OF ALFRED A. BAUMEISTER, ASSOCIATION OF MENTAL RETARDATION RESEARCH CENTERS

Senator **Adams**. I might say, as a former Secretary, I think we have all got a transportation problem, but he has got a particularly severe one, so if Dr. Baumeister would come forward, I will try to accommodate you so that you an catch your airplane. I wish you a lot of luck.

Dr. Baumeister, it is a pleasure to have you here this morning. He represents the Mental Retardation Research Center Consortium. It is a pleasure to have you with us.

Dr. **Baumeister**. Thank you, and I am very grateful and I am sure American Airlines is grateful, too. I am the director of the

John F. Kennedy Center at Vanderbilt University. It is 1 of the 12 national mental retardation research centers.

We are grateful for this opportunity to present our views concerning support through NICHD for research on children's health problems, particularly developmental disabilities. I am going to summarize some views, but request that my full statement be contained in the record.

Senator ADAMS. Without objection, your statement will appear in full in the record at this point.

Dr. BAUMEISTER. I have appeared before the subcommittee every year since 1976. Although the form, details and content of my statement have varied somewhat, on each occasion I have delivered a fairly consistent message. One is that the problem is vast and desperate—that is, the problem of developmental disabilities—both in human and financial terms.

Last year alone, for residential services we spent $12 billion for people with mental retardation, and when you add to that the educational, social, and health costs, along with lost productivity, you have a sum that might even attract attention in the Pentagon.

While we have made considerable progress toward prevention and treatment of some conditions, the scientific knowledge base is far from adequate to deal with the 350 known causes of mental retardation and other forms of mental disabilities.

I should add that many disorders among children are actually on the increase now, such as infant mortality, morbidity, partly due to cuts in health and social services, increasing environmental risks, new diseases such as pediatric AIDS, and to societal changes including alarming rates of increase of poverty among children.

One of your own colleagues, Senator Moynihan, has written a book on that subject. He seems to be getting involved in various kinds of interesting social causes these days.

We now rank 22d among nations regarding rates of infant mortality, where not so long ago we ranked about 5th. Are children to be blamed for this plight?

Under the fiscal year 1991 budget proposed by the administration the funding rate for grants for NICHD would be 22.5 percent, the lowest funding rate in the history of the institute. The President's budget calls for negotiated reductions of 15.5 percent for noncompeting projects, 12 percent for competing grants, and 21 percent in core support for research centers.

You know, Mr. Chairman, the term "negotiated reductions" sounds like a bureaucratic euphemism to me for unilateral disarmament. Nobody admits to a strategy that will sell our children short, but that is the functional result of these cuts.

PREPARED STATEMENT

I have some specific recommendations that are contained in the written statement, but let me quickly summarize a couple of these. First, we recommend an amount of funding for NICHD that will permit 40 percent of approved research grants to be funded. We also request additional funds to provide full support of the research centers, eliminated the negotiated reductions.

I thank you, Senator, for your patience and your time, and your willingness to accommodate my travel problems. Thank you.

[The statement follows:]

STATEMENT OF ALFRED A. BAUMEISTER

Mr. Chairman, my name is Al Baumeister. I am Director of the John F. Kennedy Research Center at Vanderbilt University. Appearing here today, on behalf of the Mental Retardation Research Centers, I wish to express our views concerning FY 1991 federal support, through NICHD, for research on mental retardation and related disabilities.

Mental retardation and the other developmental disabilities typically are life-long handicaps with social, psychological, and biological causes, many presenting extremely severe physical and behavioral consequences. There are over 350 different causes of mental retardation, including genetic conditions, disorders of metabolism, problems of pregnancy and birth, brain damage due to a large number of toxins, accidents, infections, and other untoward circumstances that affect development, such as poverty, undernutrition, and lack of adequate psychological and social stimulation. These are complex and costly problems.

The human and financial costs to society of mental retardation are staggering. No other human affliction creates so much suffering, for so long, and at such great consequences to the individual, the family, the community, and our nation. There are approximately 6,600,000 persons with retardation in the United States. In 1988 the total state and federal commitments to mental retardation residential services reached $11.7 billion. Add to this the enormous educational, medical and social services that must be provided and the cost is awesome, so large that even the Pentagon might be concerned.

Because the Congress earlier responded to needs of children, we have made scientific progress toward the goals of prevention and amelioration. Some research knowledge has been put into practice with outstanding results. For example, we understand the biochemistry underlying a few genetic disorders. We are now able to create medical and environmental conditions for people who only two decades ago who would have been profoundly retarded but who are now able to live normal or near-normal lives. Equally important, studies of behavior and social processes have enabled us to develop effective educationally based procedures that ameliorate many of the learning and behavior problems.

Yet, we have not solved the problems of developmental disabilities. Far from it. Despite advances in our understanding, the grim truth is that in the vast majority of instances we do not know what specifically causes retardation or how to prevent it. One fact should be made abundantly clear: mental retardation in most cases cannot be traced to a known single biomedical cause. Indeed, many forms of morbidity among children are unacceptably on the increase, circumstances recently and clearly documented in a nationally distributed publication by the President's Committee on Mental Retardation. Dr. Alexander, Director of NICHD, also brought this information to the attention of your Committee.

Evidence is now overwhelming that living conditions are strongly tied to health outcomes. Between 70% and 80% of the cases of mental retardation are linked to psychosocial disadvantage. Currently, over 12 million children are below the poverty line. As you are aware, minority groups are differentially represented. The life-style patterns and disadvantages that accompany poverty are not wholesome conditions for rearing children. Poverty contributes significantly to birth defects, mental retardation, learning disabilities and other forms of childhood mortality and morbidity. All of these considerations lead to the consensus that we require a much stronger and coherent biomedical and behavioral research base from which to proceed toward treatment and prevention.

Yet, since 1974, commitment to mental retardation research has deteriorated. For 15 years I have conducted analyses of NICHD funding patterns with particular reference to the status of mental retardation as a priority. One general disturbing conclusion emerging from these analyses is that funding for mental retardation research, both in absolute and relative terms, is in a much less favorable position today as compared with 16 years ago. Expressed in constant dollars, our research capability today is much less than half of what it was in 1975. Appended are a table and a figure showing a continuing decline in relative support for mental retardation research, from 1972 to 1989. These tabulations are based on the budget of the NICHD's Center for Research on Mothers and Children (CRMC). This is the primary organizational unit within NICHD that carries the obligation to support mental retardation research.

In FY1990 the appropriation to NICHD was $443 million. But downward negotiations were set at 15.0% for noncompeting grants, 12.0% for competing grants, and 17.1% for the research centers. This followed on the heels of similar downward negotiations in FY 1987, FY1988 and FY1989. We do not believe that this is the kind or level of response consistent with: (a) Congressional intent in creating the NICHD, (b) the gravity of the problem of mental retardation in human and financial terms and, (c) the public welfare. When one considers that the inflation rate exceeded 160% over the past 10 years, we have reached a severe crisis point for research into gravely serious health and social problems.

The Administration proposed an NICHD budget of $461,473,000 for FY 1991. That includes $29,010,000 specifically targeted on AIDS research. Under the FY 1991 proposed budget the funding rate for competing research grants would be 22.5% including AIDS. This would be the lowest funding rate in the history of the Institute. The President's budget calls for negotiated reductions of 15.5% for noncompeting projects, 12.0% for competing grants, and 21.6% in core support of the research centers. These cuts year after year are destroying our research capability, thereby sentencing more and more children to lives of disability and despair.

We understand, of course, that enormous deficits in the U.S. budget cannot continue and that adjustments must be made. But, inequitable reductions in health services, including research, hurt people--children, mothers, families--and the question must be raised: is that what we as a nation intend by way of public policy? This is not some trivial and arbitrary budgetary consideration that will merely inconvenience a few people. Cutbacks of health research capabilities are short-sighted, ultimately very costly, and constitute a grievous disservice to millions of Americans whose health, well-being, and quality of life depend on our government officials and scientists to respond.

SUMMARY RECOMMENDATIONS

We request that the implications presented in our comments be reflected in the narrative report. Improvement of mental retardation services depends on excellent basic behavioral and biological research on prevention, early diagnosis, and intervention. Emphasis needs to be directed toward an expansion of the Mental Retardation Research Centers, additional research and clinical trials in pediatric AIDS, and prevention of low birthweight, infant mortality, accidents, and other childhood disorders. In these respects we lag well behind many other societies. Our recommendations:

1. Increase funding to NICHD from $442,914,000 in the current fiscal year to $635,300 in FY1991. This is in contrast to the Administration request for $461,473,000. The amount we recommend will allow full NICHD funding of 644 competing research project grants at a cost of $138,872,000.
2. Include additional funds to provide full-cost funding of the research centers, thereby eliminating negotiated reductions. We urge that the center line be increased by $14,200,000 to enable funding seven new research centers: two new mental retardation centers, two new population research centers and three additional child health research centers.
3. Mandate that at least 25% of the extramural support provided by NICHD be for projects directly relevant to mental retardation, including a strong emphasis on prevention research.

4. Express Congressional commitment to the continuation of high-quality predoctoral and postdoctoral research training by appropriating funds in this category in the amount of $19,707,000, providing support for 800 trainees.

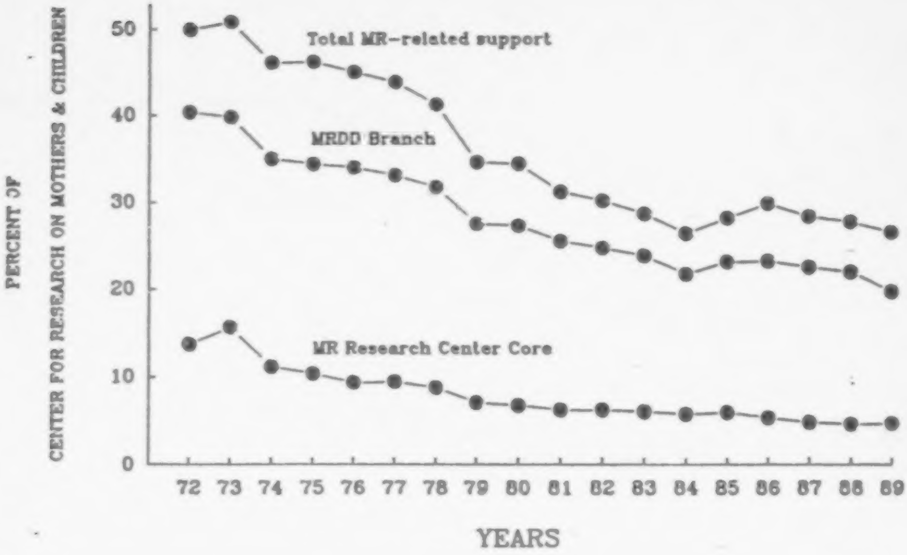
Trends in MR Funding*

(Millions of Dollars)

Year	Total CRMC Funds	Total CRMC-MR	MRDD	MRRC Core
1972	42,838,000	21,365,000	17,250,000	5,856,000
1973	41,971,000	21,330,000	16,642,000	6,533,000
1974	51,894,000	23,886,000	18,096,000	5,761,000
1975	55,094,000	25,420,000	18,884,000	5,672,000
1976	60,161,000	27,016,000	20,423,000	5,608,000
1977	64,979,000	28,419,000	21,434,000	6,166,000
1978	73,790,000	30,298,000	23,318,000	6,455,000
1979	102,492,000	35,321,000	28,121,000	6,759,000
1980	101,154,000	34,731,000	27,559,000	6,751,000
1981	106,055,000	32,997,000	26,969,000	6,623,000
1982	105,530,000	31,768,000	25,963,000	6,549,000
1983	123,346,000	35,270,000	29,306,000	7,343,000
1984	135,489,000	35,699,000	29,263,000	7,737,000
1985	157,727,000	44,329,000	36,365,000	9,298,000
1986	158,009,000	47,008,000	36,478,000	8,378,000
1987	190,505,000	54,066,000	42,726,000	9,224,000
1988	213,398,000	59,186,000	46,700,000	9,802,785
1989	228,521,000	60,462,000	45,001,000	10,638,000
Percents of Total CRMC				
1972		49.9	40.3	13.7
1973		50.8	39.7	15.6
1974		46.0	34.9	11.1
1975		46.1	34.3	10.3
1976		44.9	33.9	9.3
1977		43.7	33.0	9.4
1978		41.1	31.6	8.7
1979		34.5	27.4	7.0
1980		34.3	27.2	6.7
1981		31.1	25.4	6.2
1982		30.1	24.6	6.2
1983		28.6	23.7	6.0
1984		26.3	21.6	5.7
1985		28.1	23.0	5.9
1986		29.8	23.1	5.3
1987		28.3	22.4	4.8
1988		27.7	21.9	4.6
1989		26.5	19.7	4.7

*Source of Data: NICHD, Office of Planning and Evaluation

TRENDS IN SUPPORT OF MENTAL RETARDATION RESEARCH *



* These curves derived from data supplied by NICHD.

RESEARCH

Senator **Adams**. Thank you, Doctor. In your testimony, you stated that living conditions are often strongly tied to health outcomes. Is research currently being conducted to determine whether there is a link between mental retardation and psychosocial disadvantages?

Dr. **Baumeister**. There is a small amount of research going on in that general area, but it does not have the scale that is sufficient to address the magnitude of the problem.

Most of the research is small-scale, regular research grants rather than a larger-scale program/project type investigations that would provide the kind of data base that we would need. This is a point made very strongly by the Children's Defense Fund, by the Gutenmacher Foundation, and by many advocates before the select committee recently and within the last few years.

There is not a large-scale effort to address those problems, but every one of the health conditions that relate to disabilities, including an increase in sexually transmitted diseases, including a decrease in immunizations, decreased Federal and State support for nutritional programs, all of these are linked to the socioeconomic problems and cuts in entitlement programs.

Not only that, but I should add as well that Medicaid rules and regulations are such that they do not encourage pregnant women who are poor to seek prenatal help. I can tell you that the single and best investment we can make is to find ways to ensure free, good-quality prenatal care for women who cannot afford it. We would save billions of dollars.

We will have 8,500 babies delivered this year who weigh under 750 grams. They will cost well over $100,000 just for NICU costs. We can avoid a great many of those tragedies by supplying prenatal care to women.

Senator **Adams**. Thank you very much, Doctor. We appreciate your testimony.

STATEMENT OF THOMAS W. PURCELL, TREASURER, NATIONAL SUDDEN INFANT DEATH SYNDROME FOUNDATION/SUDDEN INFANT DEATH SYNDROME ALLIANCE

Senator **Adams**. Our next witness is Thomas Purcell of the National Sudden Infant Death Syndrome Foundation.

Mr. Purcell, welcome to the committee.

Mr. **Purcell**. Mr. Chairman, thank you very much. On behalf of the National SIDS Alliance and SIDS Foundation, we appreciate the support that you and the committee have given to this issue in the past.

I think it is appropriate, Mr. Chairman, that I follow the testimony of the gentleman who just talked about children's disorders and a variety of testimony that you have heard this morning regarding the statistics.

My statistics are that you do not have a disorder when you have SIDS, Mr. Chairman, because you are dead; 7,500 to 8,000 children a year, Mr. Chairman, die of sudden infant death syndrome [SIDS], and like most statistics it is rather impersonal.

I can speak to you as a SIDS parent. The smile, the laughing, the smallness, the cry of a child—my child was 3 months old. I came home from work trying to support my family, and she was dead. So that coldness, that unresponsiveness, that specificity, that clarity of death, Mr. Chairman, is a very frightening thing to see, when your child is 3 months old.

In 1963, the Federal Government began to look at the issue of SIDS through the NICHD, which is a part, as you know of the National Institutes of Health. Over a number of years, through really a limited action and lack of activity, Congress began to recognize the lack of activity in this area and in 1988 mandated the NICHD to develop a 5-year plan.

Well, this 5-year plan, Mr. Chairman, is to look at and develop a research agenda to expand the knowledge on the vulnerability of infant development in a series of events leading to sudden infant death. I am asking you, Mr. Chairman, to increase the funding of the second year from $5.2 million to $7.2 million, a $2 million increase, to deal with this plan.

A variety of your witnesses have talked about strategies and about a direction. You cannot have a direction, Mr. Chairman, or a strategy, that is not properly financed, that is not directed, that does not have a focus, and we need a focus. We need a direction so in the 1990's, Mr. Chairman, when we conclude this decade and we begin the next century, that we do not look back and say another 75,000, 80,000 children have died. Also, that you do not have another witness as myself to relate to you, or to your successor, that we have lost the potential, the vision, the ambition, the competitive capability, of a child.

We are a society, Mr. Chairman, of symbols, and on my lapel I have a little teddy bear, and that little teddy bear, Mr. Chairman, has a child's bracelet that is broken. What that reflects, Mr. Chairman, is the finality, the certainty, of the broken commitment, the broken life, of a child that has SIDS. When you have SIDS, Mr. Chairman, there is no discussion, there is no potential, there is no vision, there is no possibility of changing your situation. It is over.

PREPARED STATEMENT

So we ask, Mr. Chairman, that the 5-year plan that the Congress in its wisdom established 2 years ago be properly financed so that we can truly say at the end of that 5-year plan that we have identified the cause—not saying that we can rectify the cause, Mr. Chairman, but that we can identify the cause and we know the best way to deal with the Grim Reaper, that sudden infant death, in the population of our society.

Thank you, Mr. Chairman.

[The statement follows:]

STATEMENT OF THOMAS W. PURCELL

Mr. Chairman, and members of the subcommittee I am pleased to appear before you today to discuss Sudden Infant Death Syndrome. The federal response to the disorder that accounts for 7,000-8,000 infant deaths per year in this country is crucial.

If those figures get the attention of the Committee, it is also important to mention that Sudden Infant Death Syndrome is the number one cause of death in the U.S. for infants one month to one year of age.

SIDS is a tragic disorder that knows no economic boundaries and effects babies and families from every walk of life. Very little is understood about the causes of SIDS or effective methods of preventing these horrible occurrences. In the typical case, an apparently healthy infant, usually between the ages of 3 weeks and 7 months is put to bed without the slightest suspicion that anything is out of the ordinary. Some time later the infant is found dead. Mr. Chairman this is an unpleasant subject, but it is also a problem that needs to be dealt with through aggressive research, and improved services.

The National Institute on Child Health and Human Development of the National Institutes of Health is the primary federal agency that provides resources for Sudden Infant Death Syndrome research. The NICHD SIDS program began in 1963 and has maintained a very limited resource base for SIDS specific and SIDS related research. Over the years, SIDS parents, families, and SIDS professionals have been sorely disappointed by the NICHD commitment to SIDS research. Because of the recent congressional interest in SIDS, we hope this will change.

There is some hope that definitive progress can be made to shed some light on the vexing and frustrating questions that surround Sudden Infant Death Syndrome. Two years ago, Congress requested that the National Institute on Child Health and Human Development prepare a report detailing a **5-Year Sudden Infant Death Syndrome Research plan**. In response to the Committees request, the NICHD convened an esteemed group from several key scientific fields to discuss the current state of knowledge and articulate research needs. As the report confirms we are way behind in studying and preventing SIDS cases in the U.S. SIDS is a major factor that places the U.S. about 18th in the world among industrialized nations, in terms of infant mortality. Mr. Chairman, that is truly unthinkable.

The 5-Year plan enumerates a research agenda to expand knowledge on the vulnerabilities of infant development and the series of events leading to Sudden Infant Death. The research capability and technology are available and ready to conduct the studies in the 5-year plan that will hasten progress in reaching the goal of eliminating SIDS. The funding, however is necessary.

Mr. Chairman, the SIDS Foundation is very grateful that your subcommittee provided the funding last year for the first year of the 5-year plan. Because the President's budget proposal for FY'91 does not contain sufficient funds to implement the second year we respectfully urge that your subcommittee provide the necessary additional funding to move forward with the second year of the plan. Even during these times of fiscal constraint we need to know why 7,000-8,000 babies are dying each year. We also need to do something about it.

Thank you for the opportunity to present our views. I am enclosing an NICHD status report on the 5-year plan that I hope will be inserted into the hearing record.

SIDS Research Activities: Briefing for 1/22/90 Meeting

I. NICHD Supported SIDS Primary Research Projects

Fiscal Year	Funds	Number of Projects
1985	$ 1,133,000	8
1986	929,000	12
1987	2,155,000	18
1988	1,824,000	18
1989	3,193,000	23

II. Implementation of SIDS Five Year Research Plan

A. Fiscal Year 1989

SIDS Definition: On June 20, 1989, NICHD launched the plan by convening a workshop to review the scientific evidence regarding SIDS that has been gained in the last twenty years; and determine whether progress has been sufficient to revise current criteria for SIDS diagnosis, particularly for those cases which serve as a base for research on SIDS. The expert panel, chaired by Dr. L. Stanley James, Columbia-Presbyterian Hospital, was also charged with determining whether subsets of SIDS cases for research purposes could be defined based on common characteristics. The group drafted a new definition as follows: " The sudden death of an infant under one year of age which remains unexplained after performance of a complete postmortem investigation, including an autopsy, examination of the death scene, and review of the case history." An accompanying statement emphasizes that cases without a complete postmortem investigation should not be diagnosed as SIDS. In addition, the group identified common characteristics of SIDS cases and provided the NICHD with a list of information that should be required of SIDS researchers regarding the SIDS cases that they are investigating This should improve the uniformity of SIDS research and therefore lead to consistent and relevant findings. A report for publication is in the final stages of revision.

Pilot Clinical Trial of Home Monitoring: Two research proposals were reviewed in late FY 1989 for pilot randomized clinical trials of home monitors, one for apnea and one for hypoxemia. Each proposal had serious deficiencies in design and were not successful in peer review. A revision of the proposal to test a new monitor for hypoxemia is being submitted for the Feb. 1, 1990 deadline with a potential for funding in late FY 1990.

B. Fiscal Years 1990-1991

Pilot Clinical Trial of Home Monitoring: In the course of the peer reviews of the above proposals, several critical scientific issues regarding clinical trials of apnea monitors were identified. The NICHD decided to set up a forum to discuss how we can investigate the role of the maturation of cardiorespiratory function in SIDS, and the usefulness of apnea monitors. A meeting of neonatologists, pulmonary and sleep physiologists, behavioral psychologists, and neurologists was held on January 16, 1990.

The following priorities were identified:

1. Clinical studies of documented monitoring in the home of high risk infants to determine the physiologic significance of apnea and bradycardia and their role on SIDS pathogenesis. These studies will provide information on the type of event(s) that precede SIDS and hence the type of monitor(s) that should be used for efficacy trials.

2. Prospective clinical studies to identify behavioral, neurologic, and other physiologic risk factors in the first month of life that are predictive of SIDS.

3. Development of home monitors for obstructive apnea and oxygen desaturation.

4. When the studies in outlined in (1) above are completed, a randomized trial of appropriate monitors to prevent SIDS deaths can be conducted.

An initiative(s) will be developed and released in FY 1990 for funding in FY 1991.

Interagency Panel on SIDS: Biomedical research, surveillance, and health service delivery regarding SIDS are under the auspices of several components within the Public Health Service, with related responsibilities in other parts of the Federal Government. In addition new legislation has been enacted which is not limited to SIDS but has implications for sudden and unexpected deaths of infants. There is considerable interest in establishing a group of relevant staff to meet regularly to exchange information about these activities, enhance productivity through collaboration and coordination, and develop new strategies to understand and combat SIDS. A meeting of staff concerned with infant mortality and SIDS to include the following agencies: CDC, NCHS, HRSA, NIH, IHS, ADAMHA is being held on Feb. 6, 1990 to share current activities and to discuss the establishment of the Interagency Panel on SIDS.

SIDS Data Acquisition: The discussions on Feb. 6. will help to identify ongoing or new studies that will illuminate SIDS risks factors. For example, NICHD is currently planning a joint project with IHS and HRSA to investigate the unusually high incidence of SIDS among the Northern Plains Indians.

Role of Infections in SIDS: NICHD staff is meeting with staff from NIAID in early February to define the scientific issues to be presented at a workshop on the role of infection and the infant's immune response in SIDS. We are focusing on the immune response to respiratory and gastrointestinal infections that are reported to be increased in SIDS victims within the two weeks prior to death.

III. Research Progress and Future Research Directions

A. Cardiorespiratory Control and Sleep

Analysis of recordings of respiratory and heart rate during the first month of life of infants who later died of SIDS has shown that SIDS babies are not normal physiologically at birth and has provided evidence that the central nervous system control of cardiorespiratory function in these babies is abnormal. For example the respiratory related variability of heart rate is depressed in specific sleep states in SIDS victims and these differences are greater at particular times of the night.

Action:

1. The above studies have been funded for an additional three years to perform more sophisticated analyses of the physiologic variables of SIDS victims during sleep and how their sleep state organization matures.

2. This information will be used to design the prospective physiologic studies of SIDS risk.

3. This information is being used to design animal model studies of the development and function of nervous system centers involved in

cardiorespiratory control during sleep. A grant proposal has been submitted.

4. A Small Business Innovation Research Grant to develop a cardiac monitor that incorporates our knowledge of alterations of heart rate variability during sleep in infants at risk is being funded this spring.

B. The Nervous System of SIDS Victims

We are supporting four research projects which investigate the structure and neurochemical composition of the nervous system of SIDS victims. Two projects involve detailed quantitative studies which will be invaluable when completed. We have learned thus far that the peripheral organs that sense the degree of oxygenation of the infant are abnormal in SIDS babies and that the centers of the brain involved in the regulation of cardiorespiratory control are delayed in maturation.

Action:

1. One of these studies has been renewed for an additional three years to see it to completion; the others are in their first funding cycle.

2. The information will be used to develop animal models to investigate how these nervous system abnormalities can be generated and prevented. Three new grants have been funded in FY 1989 toward this goal.

3. The anatomic data in conjunction with the physiologic information that we have on SIDS victims will aid in the design of the prospective studies of SIDS risk.

C. Predictive Tests for SIDS

We have just completed support of two phases of a Small Business Innovation Research Grant on the predictive value of cry analysis in SIDS. Twenty-six thousand babies were enrolled at birth and their cries recorded in the first few days of life. Analysis of the data will be complete when the one year follow-up for SIDS deaths ends this spring. Thus far the predicted number of SIDS deaths have occurred, ensuring an adequate data base for analysis.

Based on the beliefs that SIDS victims are hypoxic and delayed in maturation, scientists have examined the fetal hemoglobin levels of SIDS infants and controls. It was reported that SIDS victims have increased fetal hemoglobin levels compared with normal infants and that fetal hemoglobin screening may have the potential for identifying infants at greater risk for SIDS. This is an important finding that warrants corroboration. Currently, four NICHD supported investigators are studying fetal hemoglobin, three in specimens from SIDS victims and normal infants, and the fourth in a lamb model where the interaction of developing hypoxia and fetal hemoglobin can be studied.

For the last two years we have supported investigations to search for metabolic abnormalities in autopsy tissues of SIDS victims, based on the estimate that 5-10% of SIDS deaths are caused by inherited metabolic disorders. This year we have expanded this research area by funding a research project that looks for new inherited metabolic disorders in living infants with clinical symptoms that may precede sudden death such as apnea, developmental delay, and hypotonia. The investigation will include defining the metabolic abnormalities from biochemical investigations of biopsy material from these infants, developing diagnostic tests for the disorders at birth, and developing nutritional interventions to prevent symptoms and death. The investigators have obtained evidence for a new metabolic disorder with no severe symptomatology prior to the terminal event and no pathology.

Action:

1. If characteristics of infant cry reflect neurologic impairment in subsequent SIDS victims, cry analysis can be incorporated into prospective studies of SIDS risk.

2. The SIDS Five Year Plan calls for an initiative in FY 1992 to evaluate automated newborn screening technology for inherited metabolic diseases that present as sudden death.

D. Animal Models

NICHD supported research on respiration and sleep in animal models has increased our understanding of how chronic oxygen deprivation can alter an infant's survival mechanisms. In lambs, the carotid body, a peripheral chemosensory organ, must be functioning in order for the lamb to arouse to a rapidly developing hypoxemia (low blood oxygen). This finding is significant because another grantee has observed that the structure and chemical composition of the carotid bodies of SIDS victims is abnormal. In addition it has been established that in lambs, repeated exposure to lack of oxygen reduces the arousal response to hypoxemia, reduces the normal respiratory response to an acute loss of oxygen, and increases apnea under specific conditions. This research provides clues as to how chronic hypoxia depresses respiratory function and may put an infant at risk for apnea.

For future work on the development of autoresuscitative mechanisms, mouse strains have been identified that exhibit differences in the ability of weanling but not newborn or adult mice to recover from apnea induced by oxygen deprivation.

Action:

Develop animal models which investigate how other fetal and postnatal insults working alone or in conjunction with hypoxia can cause cardiorespiratory deficiencies and nervous system pathology reminiscent of SIDS. Using knowledge regarding the physiology and neurochemistry of SIDS victims, test interventions in animal models. A workshop to identify the issues to be addressed in animal models and the types of animal models to be studied is being planned for FY 1990. An initiative will be developed based on these discussions for funding in FY 1991.

E. SIDS Diagnosis

Two activities by the NICHD will improve SIDS diagnosis. The first, as described above, is a revised definition of SIDS that requires a full postmortem investigation for the diagnosis. The second is the development of the SIDS Histopathology Atlas that is derived form the cases collected for the NICHD Collaborative SIDS Epidemiologic Study. This atlas will serve as a reference for general and forensic pathologists to guide them in classifying death as SIDS from the autopsy. The atlas educates pathologists with pictures and narrative for all organ system and provides guidance in those cases where the diagnosis is difficult to make.

Action:

1. Disseminate knowledge regarding the SIDS definition and Histopathology Atlas by working with HRSA, relevant medical societies, and SIDS organizations.

2. Encourage the establishment of national legal requirements for postmortem investigation of SIDS deaths and uniform coding of SIDS deaths. This will be done through the Interagency Panel on SIDS and by working with SIDS organizations.

Senator **Adams**. Thank you, Mr. Purcell, for a very moving and important amount of testimony. I have been familiar with your group and with its beginnings, and was very involved with a number of the people in Seattle very early on. It is one of the great tragedies of America, and I appreciate you bringing it to the committee. We will do what we can to see if we cannot assist in trying, as you say, to at least find the cause.

Thank you very much, Mr. Purcell.

Mr. **Purcell**. Thank you, Mr. Chairman. Thank you for your time.

STATEMENT OF JOHN. R. DAVID, PRESIDENT, AMERICAN SOCIETY OF TROPICAL MEDICINE AND HYGIENE

Senator **Adams**. Our next witness is Dr. John R. David, president of the American Society of Tropical Medicine and Hygiene.

It is a pleasure to have you with us, Dr. David.

Dr. **David**. Senator Adams, could I request that my printed statement please be put in the record?

Senator **Adams**. Without objection, your entire statement will appear in the record as though read.

Dr. **David**. I am John David. I am professor and chairman of the Department of Tropical Public Health at the Harvard School of Public Health, and I am testifying on behalf of the American Society of Tropical Medicine and Hygiene, of which I am president, on the urgent need to increase Federal support of tropical medicine, in particular, in biomedical research and training in general.

The worldwide devastating impact of tropical diseases arouses humanitarian concerns and creates a golden opportunity for the United States to help stabilize developing nations which are the home of over 75 percent of the world's population and where 98 percent of all infant and child deaths occur each year.

Malaria alone kills over 1 million children a year. Furthermore, dozens of tropical infections pose a direct threat and a costly threat to U.S. citizens both abroad and at home, a threat that is increasing because of jet travel, because of international business, and because of increased rise of organisms that are drug resistant.

For example, in the United States toxoplasmosis, a parasitic disease, leads to blindness, mental retardation, and epilepsy of over 4,000 children a year at the annual cost to the taxpayer of over $500 million. Research in this area leading to the prevention of just this disease would save much suffering and money.

I was glad to hear that Senator Lieberman also mentioned Lyme disease, which because it is tick borne is generally under the purview of people working on tropical medicine and also is a major problem in the United States.

I have spent 30 years of my life in research and teaching and training scientists, and now, due to the level of funding I look around me and I see that these areas are starting to collapse. Excellent and established investigators are not being funded. Scientists are leaving academic research, and young people are not coming to replenish the field. To me, it looks like a recipe for disaster.

These deficiencies have been documented in two detailed assessments by experts, the one by the Office of Technology Assessment of the Congress in 1985, the other by the Institute of Medicine in 1987, and what they have described has only worsened since these were printed.

Today there is a critical shortage of funds for biomedical research and training. Funds are not sufficient to keep up with the scientific needs. For example, 17 percent—less than one in five—scientifically approved grants are now being funded by the National Institutes of Allergy and Infectious Disease.

That means that 83 percent of scientifically approved grants are not being funded, and the President's 1991 budget will not change these matters at all. Our society strongly supports the recommendation that $9.2 billion be the minimal funding for the NIH's research and training program.

PREPARED STATEMENT

In conclusion, an investment in tropical medicine will serve the United States well by improving our capacity to cope with tropical infectious diseases threatening our country, by advancing the health and stability of developing countries and by promoting the advancement of science, and I would like to also thank you for inviting me to speak and also for your backing of biomedical research in the past.

Thank you, and I would be happy to answer any questions.

[The statement follows:]

STATEMENT OF JOHN R. DAVID

Thank you Mr. Chairman. My name is John R. David and I am Professor and Chairman of the Department of Tropical Public Health of the Harvard School of Public Health. I am testifying on behalf of the American Society of Tropical Medicine and Hygiene (ASTMH), a professional society of basic and clinical researchers and practitioners in the field of tropical medicine. I would like to request that my written statement be placed in the record.

I thank the Chair and the Members of this Subcommittee for this opportunity to testify, as well as for your support of biomedical research programs over the past decade. In addition, we were pleased to learn of the Subcommittee's interest in tropical diseases as shown by its request for a report from NIAID on the Status of Tropical Medicine Research at NIH.

The ASTMH urges this Subcommittee to continue its record of support for biomedical research in FY 91. In our view, increased Federal support for the type of research and training that is the unique province of NIH is the greatest need for tropical medicine in particular, and for biomedical research in general.

Background

The devastating worldwide impact of tropical diseases arouses humanitarian concerns for the well-being of others, and creates a golden opportunity for the U.S. to help stabilize the developing nations that are home to 75% of the world's population and where 98% of all infant and child deaths occur. Malaria alone accounts for over 2 million child deaths each year. I know that some of you have visited refugee camps, famine areas, and some of the poorest areas of the developing world. You have seen first hand the devastating problems that we are trying to solve.

In fact, dozens of tropical diseases (e.g., malaria, dengue, schistosomiasis) pose a direct and costly threat to the lives and well-being of U.S. citizens, traveling or living abroad, and here at home. This threat has increased for many reasons, including frequent jet travel, overseas business opportunities, changes in the environment, and the increase in drug-resistant organisms.

Research and experience in tropical medicine provide numerous benefits to the American public, are vital to military preparedness, and would create a base for economic development of the third world. Tropical medicine specialists provide the expertise to respond to the emergence of deadly tropical infectious diseases, such as Lassa fever and AIDS, and many parasitic and other diseases not strictly "tropical," such as Lyme disease and toxoplasmosis. In the U.S. alone, toxoplasmosis, a parasitic disease, leads to blindness, mental retardation, and epilepsy in over 3,000 infants a year, resulting in an annual cost to American taxpayers of over $430 million. Research leading to the prevention of this disease would save us much suffering and money.

Furthermore, tropical medicine has provided cost-effective means to conquer or control diseases such as yellow fever and smallpox. More recently, researchers in tropical medicine have made significant gains in the struggle to develop vaccines against malaria, leishmaniasis, and toxoplasmosis, as well as fundamental scientific advances in our knowledge of mechanisms of diseases, action of newer drugs, and immunoregulation in chronic infection.

Federal support for research and training in tropical medicine has its main focus in the National Institute of Allergy and Infectious Diseases at the NIH. Unfortunately, over the past decade, the level of support for this research and training has been declining, and with it, the U.S. capacity for dealing with tropical diseases is waning.

I have spent the last 30 years of my life doing research, teaching and training people, and working in the field. I am sad to tell you that I see all of these areas collapsing around me. Excellent and established people are not being funded, scientists who we have invested huge amounts of money and effort in training are leaving academic research, and young people are not coming into the field. The levels of frustration, anger, and disappointment are enormous. If this is not a disaster, what is?

These deficiencies have been documented in two detailed assessments of the field by expert analytical agencies. Although the reports are now a few years old, the conditions they describe have worsened. We recommend both reports to the Subcommittee: Status of Biomedical Research and Related Technology for Tropical Diseases (1985) by the Office of Technology Assessment; and, The U.S. Capacity to Address Tropical Infectious Disease Problems (1987) by the Institute of Medicine.

Research Funding

Today, our most critical deficit is in the area of direct funding for research. The level of funding for tropical disease research is not sufficient to keep pace with scientific needs. For instance, fewer than 1 out of 5 of the National Institute of Allergy and Infectious Disease's scientifically approved grants are currently funded.

In FY 90, NIAID expects to fund 1,624 non-AIDS research grants--which represents less than 20% of approved competing grant applications. Grant awards are then followed by cuts, not so cleverly described as "downward negotiations," equivalent to 10-14% of the grant award up front, to be followed by additional cuts in subsequent years. The President's budget for FY 91 does not call for any increase in the number of non-AIDS grants or even for full funding of research grants. In fact, under the President's FY 91 budget, the number of research grants would not be increased at all, nor would those that are funded be spared the undeniable damage of downward negotiations.

I cannot overstate how strongly ASTMH supports effort to increase funding for basic and applied research. Right now, a multitude of research opportunities remain unfunded, in areas ranging from rapid diagnosis, effective treatment and vaccine development, to insect vector biology, and molecular biology and field studies. The ASTMH supports the recommendation of the Ad Hoc Group for Biomedical Research calling for $9.2 billion for NIH as the minimal level of funding for NIH's research programs. Funding of NIH at the level recommended by the Ad Hoc Group will allow for funding of 33% of approved competing grants at NIAID and will allow full restoration of grants, i.e., without downward negotiations. However, in an ideal world, free of large budget deficits, the judgement of researchers in the field would call for funding rates of 40-45%.

Training

While the need for properly trained medical research scientists in general is great, these needs are particularly acute in the field of tropical medicine. The number of qualified and experienced professionals is decreasing as the ranks of professionals recruited and trained during wartime are depleted by retirement and death. Young would-be investigators, discouraged by the now-dim prospects for research funding, are not replenishing these ranks in sufficient numbers. It would be a sad commentary if sufficient professionals in this unique area of medicine could not be trained without another war.

To make the situation more depressing, collaborative activities with scientists from the tropics are consistently underfunded, resulting in lost opportunities for clinical and field research and training of U.S. scientists in less-developed countries whose conditions can not be duplicated in a U.S. laboratory. The President's FY 91 Budget again calls for no increase in training at the NIAID. The ASTMH supports the training funding levels recommended by the Ad Hoc Group which would allow for full funding of existing training positions at NIH.

Animal Use in Research

Finally, I would like to comment on the critical need for the use of animals in biomedical research today. They are essential for progress in medical research. The safety of researchers, research subjects, and research investments requires the support of the Congress. ASTMH appreciates and applauds your support for and successful passage of the Heflin bill in the last session of Congress. Such measures are essential to provide the legal protections so necessary in this crucial area.

Conclusion

In conclusion, the American Society of Tropical Medicine and Hygiene is committed to seek increased levels of funding for biomedical research and training in tropical medicine. ASTMH believes that a modest investment in tropical medicine will serve the United States well by improving our capacity to address the problem of tropical diseases being constantly imported into the U.S. , making a humanitarian and humane contribution overseas, and contributing to the advancement of science.

This concludes my formal statement. I would be pleased to answer any questions that the Subcommittee may have.

Senator **Adams**. Thank you, Doctor. You strike a very familiar note with me in that my daughter came back from Nepal with we do not know what-all yet. One of my best friends, Michael Forrestal, and I spent a lot of time in Algeria and contracted things that—we are not at all certain what he finally had.

It is a field that I think deserves a great deal of research, not just for infants, but if we are to send both our students, our children abroad. If we are to function in various nations throughout the world, a great deal needs to be done in that generally, with most of us, if we make a mistake, it is fatal. So I appreciate very much your being here today. I will reread your testimony, and if you have anything additional you wish to submit to me, I would be most interested in receiving it.

Dr. **David**. I thank you very much.

STATEMENT OF GAIL ZIMMERMAN, COCHAIRMAN, COALITION OF PATIENT ADVOCATES FOR SKIN DISEASE RESEARCH

ACCOMPANIED BY:

LADONNA WILLIAMS, ECZEMA ASSOCIATION FOR SCIENCE AND EDUCATION

ANNETTE SKALONE, UNITED SCLERODERMA FOUNDATION

Senator **Adams**. Our next witness is Gail Zimmerman, cochairman of the Coalition of Patient Advocates for Skin Disease Research.

Ms. **Zimmerman**. I want to thank the chairman and the committee for giving this opportunity to testify regarding the budget of the National Institute of Arthritis, Musculoskeletal and Skin Diseases, and I would like to take a moment here just to introduce my companions.

On my right is Mrs. Ladonna Williams, who represents the Eczema Association for Science and Education. Ms. Williams has two children with severe eczema, and on my left is Mrs. Annette Skalone, representing the United Scleroderma Foundation, and Annette has systemic scleroderma.

The coalition represents 12 national lay skin disease organizations that are directed and supported by skin disease patients and their families.

All of the organizations that are members of the coalition have patients who have received significant benefits from the Federal Government directed through the National Institutes of Health.

Specifically we are here today to ask the committee to consider increasing the NIAMS's budget by $50 million over what the President's budget requests. This amount was developed by the NIAMS's coalition of professional and voluntary health organizations, and we support their recommendation that this additional funding will put the new Institute on a parity with the other Institutes.

We appreciate the committee's and the Congress' creation of this new Institute. It is giving great benefit, I might add, to skin disease research in general. If I just may make an aside here, because the word skin was added in that Institute title—just because of that simple act—the skin disease patients for the first time have been represented in the NIH councils and committees, and it has given us a great opportunity to become much more educated about the issues and to be more effective. So for that we are very appreciative.

I would like to just say that all of the diseases that our coalition represents are disfiguring, disabling, and life threatening. We estimate that approximately 13 million people in the United States have one of the disorders represented by our coalition, and of that 13 million, we estimate that at least 2 million die or are so disabled by skin disease that they cannot work or they are emotionally or functionally disabled.

Just to show you an example of one of the diseases, eczema, Mrs. Williams has a photograph of a 40-year-old man with lifelong atopic eczema, who had severe eye problems. The eczema gets in the cornea, and he had to have corneal transplants. Mrs. Williams also has photographs of her child.

Senator ADAMS. Do you wish this to be made part of the record?

Ms. ZIMMERMAN. Yes.

Senator ADAMS. Without objection, these photographs will be received into the subcommittee files.

Ms. ZIMMERMAN. Mrs. Williams also has a photograph of her son, who is in a reasonably good state at that point, that has eczema.

We wanted to share those photographs with you because sometimes skin disease is appreciated as a minor problem, and it can be quite serious.

And I want to say that the NIH has been a chief source of hope with patients afflicted with skin disease. Skin disorders such as psoriasis have had treatments available to provide some relief, and many of the disorders, though, have no treatments at all. Research at the NIH has helped to develop the current treatments for many of these patients or open up avenues of research that offer the first hope of treatment.

I would like to give two examples of the ways in which NIAMS has helped people with skin disease most recently. The first is the development of Tegison, which was approved in 1986, that is an oral drug that is very, very effective in treating a rare and severe form of psoriasis called pustular psoriasis. It is life threatening and approximately 500 people die from it. This drug has almost eliminated that. It clears up pustular psoriasis in a hospital within 1½ weeks.

I personally met one young man who had been bedridden with pustular psoriasis. He was 16 years old. He faced a life really of—he had no life. He could not get out of bed. Tegison cleared him completely, and he is now 26. He was on the experimental program. He has a career as a video photographer and he is functioning ably.

Another example is recent efforts in unlocking the mystery behind dystrophic epidermolysis bullosa, a severe and life-threatening disease has yielded new information on skin proteins. Last week, one of the NIH scientists told me they only thought there were two proteins in the skin. They now find there are up to 20, and there are probably many more, and he is very hopeful that by finding all of these proteins, this will lead to a much better understanding of not only EB, but many other diseases including psoriasis. Skin disease research in our view holds great promise. We are on the lip of starting to make major advances in skin disease. The thing that scares us the most, if I may depart a little bit of what I have written here, is that there are no young scientists coming up. We sponsored a psoriasis workshop in Deer Valley, UT, last September with money from NIH. It was the first time a meeting had been held on psoriasis research in 20 years that involved multidisciplinary scientists.

And in that room there was not one scientist under the age of 50. I asked a couple scientists in the room who was going to follow in their footsteps if no cure was found, and they essentially said, well that was not their problem; they did not know where new scientists were coming from. We had great concerns looking in that room, wondering it is wonderful to have this research going on, but when these men or women depart the scene, who is going to pick it up from them?

PREPARED STATEMENT

That was an alarming thing to us. And I would say that is our biggest concern right now is the labor shortage, apparently that is occurring in science. And just now as skin disease is starting to have a chance to really breakthrough, it would be a shame not to have people being able to carry on.

With that, I would like to conclude by saying that we do support the $50 million addition, and we are very appreciative to the Congress for all they have done for skin disease research.

Thank you.

[The statement follows:]

STATEMENT OF GAIL M. ZIMMERMAN

Mr. Chairman and members of the subcommittee, on behalf of the Coalition of Patient Advocates for Skin Disease Research (CPA/SDR), I want to thank the Chairman and the Committee for giving us this opportunity to testify regarding the budget of the National Institute of Arthritis, Musculoskeletal and Skin Diseases of the National Institutes of Health. The Coalition represents 12 national skin disease organizations that are directed and supported by skin disease patients and their families.

All of the organizations that are members of the Coalition have patients who have received significant benefits from the federal government directed through the National Institutes of Health. We, therefore, are here today to ask that the budget of NIAMS be increased this next fiscal year by $50 million, the amount which the NIAMS Coalition groups and ourselves feel will put the NIAMS Institute on comparable footing with the other Institutes. We appreciate the Congress' creation of this new Institute and want to thank you for this act which will have significant, positive health benefits for the many millions of people who suffer with skin disease.

All of the diseases that our Coalition represents are disfiguring, disabling, and/or life-threatening. We estimate that approximately 13 million people in the United States have one of the disorders represented by this Coalition. And of that 13 million, we estimate that at least 2 million die or are so disabled by skin disease that they cannot work or are functionally handicapped. The NIH, namely through the NIAMS, is the chief source of hope for patients afflicted with these diseases. Though skin disorders, such as psoriasis, have treatments available to provide some relief, many of the disorders have no effective treatments.

Research at the NIH has helped to develop the current treatments for many of these patients, or open up avenues of research that offer the first hope of treatment. I would like to give you two examples of what I mean:

The NIH assisted in developing a retinoid drug called Tegison, approved in 1986, which has restored a normal life to many patients who are afflicted with a severe and rare form of psoriasis called pustular psoriasis. One young man helped by this drug developed pustular psoriasis at the age of 16. The disease was so severe that it caused him to be bedridden and kept out of school. Tegison enabled him to regain normal function and to resume school. That young man, now 10 years later, is still on the drug, has finished college and has begun his career. It is hard to say what would have happened to him without this drug.

On another level, recent efforts in unlocking the mystery behind what causes dystrophic epidermolysis bullosa, a severe and life-threatening skin disease, has yielded new and significant information on proteins in the skin which could ultimately lead to a better understanding of a variety of skin diseases.

Skin disease research holds great promise, in our view. With all the recent advances in molecular biology we have strong reason to believe that the future holds great promise for the application of these new findings to the area of skin disease. However, we are concerned that these applications will not be made, that these gains will not be realized. The declining percentage of grants being funded by NIAMS and the NIH, in our view, threatens to erode the current scientific base in the United States to make science less attractive as a career to young people and to work against innovative grants being funded. We are especially concerned that fewer young people will choose basic science as a career path and that fewer scientists will be available to meet the needs of research. We are concerned that a vigorous research base be maintained in this country and we feel that the NIH is central to maintaining that vigor.

We respectfully submit to the Committee a request that the NIAMS budget be increased by $50 million which will put it at parity with the other NIH Institutes in terms of the percentage of approved grants funded, increasing it from 16.6 to 28 percent; train 60 additional researchers; support more clinical trials that are urgently needed; fund more skin research centers and add $7 million to the intramural research program. This increase to NIAMS would place it on a proportionate footing with the other Institutes as well as to help protect the scientific advances achieved to this point. We thank the Congress for its support of biomedical research funding and we hope you will continue to make investments in science.

PUBLIC FUNDING

Senator ADAMS. Thank you very much, Ms. Zimmerman.

In conjunction with the public funding, what roles should the drug manufacturing companies play in collaborating with the development of new drugs for skin disease? This seems to be the method of distribution, and I assume they are placing great amounts of money in this because it is both very debilitating and an area where people are very conscious of it.

Ms. ZIMMERMAN. Yes; it is interesting. Psoriasis actually out of all the members of the coalition is the only disease that has many treatments. Scleroderma, for example, has none, and the drug companies have not done much in that area at all, and I am not sure why.

Senator ADAMS. What about severe eczema?

Ms. WILLIAMS. They are working on new medications to prevent use of steroids—the oral steroids, which can be more complicated sometimes than the disease itself.

Senator ADAMS. Thank you all very much for your testimony. We appreciated it.

STATEMENT OF EDWARD S. HORTON, CHAIRMAN, NATIONAL DIABETES ADVISORY BOARD

Senator ADAMS. Our next witness will be Dr. Edward S. Horton, chairman of the National Diabetes Advisory Board.

Dr. HORTON. Good morning, Senator Adams. Thank you for giving me the opportunity to appear before you today to present the recommendations of the National Diabetes Advisory Board. My name is Edward Horton. I am chairman of the department of medicine of the University of Vermont College of Medicine. My entire professional career has been spent in research and teaching and patient care in the diabetes field. And I am currently president-elect of the American Diabetes Association, as well as serving as chairman of the National Diabetes Advisory Board.

The National Diabetes Advisory Board was established by Congress to review the Federal Diabetes Program and make recommendations for future directions. Our annual report will be provided to the subcommittee as soon as it is received from the press, and I have submitted a copy of the text of my remarks today, which I would request would be entered into the record.

Senator ADAMS. Without objection, your remarks will appear in the record in full, as though given.

Dr. HORTON. Thank you. I would like to use my 3 minutes of your time to highlight four of our recommendations.

The first recommendation is that $525 million be appropriated to the National Institute of Diabetes, Digestive, and Kidney Diseases to support investigator-initiated research programs. This is really the backbone of my medical research throughout NIH, and we have seen an alarming trend during the past 4 years in the ability to sustain funding for these programs. Four years ago approximately 40 percent of approved research grants from NIDDK were funded. We have seen this drop in progressive years from 40 percent to 32 percent to 23 percent and, for the current fiscal year, an estimated 18 percent of approved grants being funded. And it has only been maintained at the 18 percent level because of a 12.5-percent across-the-board negotiated reduction in existing grants. This is having a major impact. Well-established research laboratories are no longer able to carry on the very important work in diabetes research and with an increasing difficulty in attracting young, new investigators into the field of diabetes.

Our recommendation of $525 million would bring the funding level back up to the 40 percent that it was 4 years ago, and we think this is very important in order to maintain our leadership in diabetes research.

We have two recommendations that I would like to highlight that are special initiatives.

One is that we would like to recommend that $10 million be appropriated for an initiative to bring into diabetes research the new advances in genetics and molecular biology, which are providing us with the techniques for developing preventions and cure of many diseases in our society.

We find that there are not enough people trained in these techniques, applying their skills to diabetes research, and we believe that a major interdisciplinary research initiative needs to be initiated to bring these skills into diabetes research.

The second special initiative is to target funding to go into research on the relationship between diabetes and cardiovascular disease. People with diabetes have a two to threefold increased risk for developing heart attacks, strokes and other manifestations of cardiovascular disease. The relationship between diabetes and cardiovascular disease is not well understood, and we feel that a special initiative in this area is very much needed.

PREPARED STATEMENT

Our final recommendation is to increase the funding to the Centers for Disease Control by $6 million. The CDC has the responsibility for taking the latest developments and by medical research and translating that into practical care—improved care for people with diabetes in order to bring the latest developments in research out to the community.

So those are the four recommendations I would like to highlight at this time. I appreciate having had this opportunity to present them to you.

[The statement follows:]

STATEMENT OF EDWARD S. HORTON

The National Diabetes Advisory Board was established by Congress to review Federal diabetes programs and make recommendations for future directions. Our annual report has been provided to the Subcommittee.

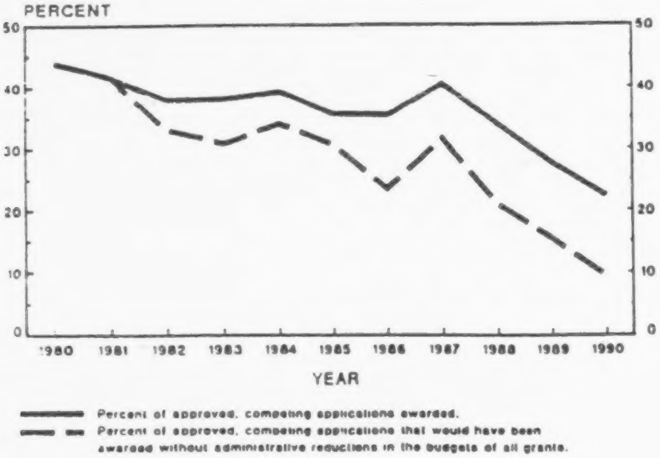
Diabetes is one of the leading causes of death and disability in this country. It frequently results in life-threatening complications that lead to premature heart disease, stroke, blindness, renal failure, amputation of extremities, loss of nerve sensation, early loss of teeth, and babies born with birth defects. A major portion of the economic burden of diabetes is paid by Medicare, Medicaid, and other Federal health care programs.

Federal diabetes research programs were expanded between 1976 and 1980, following the report by the National Commission on Diabetes. This augmented research effort led to considerable progress in the prevention of vision loss, treatment of diabetic end-stage renal disease, management of diabetes in pregnancy, and in pancreatic transplantation. Unfortunately, this brief expansion ceased by 1980, and since then appropriations for diabetes research programs have not kept pace with the costs of biomedical research. This trend is having a serious impact on diabetes research at a time when we are closer to understanding the basic biological mechanisms involved in the genesis of diabetes, its clinical course, and its associated complications.

National Institute of Diabetes and Digestive and Kidney Diseases

The impressive gains made in diabetes research in the past are largely due to research supported by individual investigator-initiated research project grants. However, the percentage of approved applications for diabetes-related research that can be awarded has declined precipitously in the past decade. At the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), the award rate has fallen from 44 percent 10 years ago to 22 percent in FY 1990. Moreover, since 1982, the budgets of all awarded grants also have been reduced below the amounts approved by the scientific review committees. This reduction reached 12 percent in 1990. If these reductions had not been implemented, the actual award rates for competing applications would have declined even further, as shown below.

AWARD RATIO FOR COMPETING RESEARCH APPLICATIONS
NIDDK, 1980-1990



The failure of Federal appropriations to keep pace with new research opportunities and the rising cost of biomedical research are seriously affecting established research programs and deterring future scientists from entering research careers. The Board believes that at least 40 percent of approved individual research grant applications should be funded at budget levels approved by the scientific review committees.

The Board recommends that Congress and the administration provide $525 million in FY 1991 for research project grants in NIDDK to support 40 percent of approved projects at recommended budget levels.

In the past decade, developments in molecular biology, recombinant DNA technology, molecular genetics, monoclonal hybridoma technology, immunology, and molecular virology have led to major scientific advances. The effort to control diabetes is ideally suited for a multidisciplinary approach using the new knowledge and technologies of basic science. However, insufficient numbers of investigators trained in these disciplines currently apply their expertise to diabetes research, and NIDDK does not have the fiscal resources to initiate new programs in this area.

To address this urgent need, the Board recommends the establishment of a Diabetes Interdisciplinary Research Program at NIDDK. The goal of this initiative is to create new research avenues and opportunities toward the prevention of diabetes and the control of its devastating complications by applying the emerging techniques of basic science to specific diabetes research issues. For example, recent advances in molecular genetics now provide unprecedented opportunities to identify and characterize the specific genetic mechanisms that determine an individual's risk of developing diabetes and its complications. Additional funds should be appropriated specifically for this program.

The Board recommends that an additional $10 million be provided to NIDDK in FY 1991 to support a Diabetes Interdisciplinary Research Program.

Cardiovascular disease is the major cause of morbidity and mortality in people with diabetes--they develop it earlier in life and are twice as likely to die from it compared with the general population. Although it is evident that diabetes is a major independent risk factor for cardiovascular disease, the precise linkage between diabetes and heart disease is unknown.

Basic research information on the relationship between diabetes and cardiovascular disease is very sparse and must be developed before meaningful clinical studies of therapeutic interventions can be undertaken. Additional investigator-initiated research must be supported to identify the causative factors that lead to increased cardiovascular mortality among people with diabetes. The Board urges the appropriation of additional funds for this targeted program to elucidate the factors that underlie this devastating and life-shortening complication of diabetes.

The Board recommends that an additional $5 million be appropriated to support research on the etiology, pathogenesis, prevention, and treatment of cardiovascular disease in diabetes.

The total NIDDK budget must be increased to support the above new activities and to continue the other important programs conducted by the Institute.

The Board recommends a total appropriation of $745 million in FY 1991 for the National Institute of Diabetes and Digestive and Kidney Diseases.

Centers for Disease Control

The Centers for Disease Control (CDC) supports a targeted diabetes program to reduce unnecessary morbidity and mortality by facilitating the widespread application of diabetes research results. This program is an essential component of the national diabetes long-range plan, and additional funds should be provided to implement all program components previously recommended by the Board.

The congressional appropriation for CDC should be increased by $6 million in FY 1991 to fully support the development of the entire diabetes control program recommended for CDC.

In summary, the Board believes that efforts to control and prevent diabetes must be a national priority. Federal funds spent on diabetes activities today can prevent greater Federal spending for patient care in future years.

HUMAN GENOME

Senator ADAMS. Doctor, I think you have answered this, but I want to confirm it to be certain. Is it your opinion that the mapping of the human genome by the new National Center for Human Genome Research would contribute to further advances in molecular genetics?

Dr. HORTON. The human genome project is a very important part of the overall biomedical research effort, yes, sir. And it does have direct application to diabetes.

In addition to that, however, they are many aspects of molecular biological research now that are not only to identify what is probably more than one gene involved diabetes: there is a susceptibility gene, there are genetic defects that may relate to abnormalities in the immune system that are so important in the development of the type I or insulin-dependent diabetes. There may be genetic defects leading to insulin resistance, which may be at the root of the development of type II or noninsulin-dependent diabetes. The genetic techniques that are being developed can also be applied in the transplantation field, which gives us hope for at least a cure through islet cell transplantation. So there are many avenues.

Unlike the recent discovery of the gene causing cystic fibrosis, we think there are many genes that are critically important to understanding diabetes and thus leading to prevention and cure.

Senator **Adams**. In your testimony you mentioned that diabetes and its relationship to cardiovascular diseases and numbness and amputation of portions of limbs and so on. Is this something that develops later in life with cardiovascular problems leading to a diabetic condition as well as a diabetic condition leading to the cardiovascular disease? I know the two seem to combine and I never understood what comes first, and whether numbness and so on is a result of cardiovascular, which diabetes then comes to lead to——

My father died from this with a toe at a time and a leg at a time and so on. And he had diabetes at the end of his life, but he did not at the beginning. Are they tied together in that fashion?

Dr. **Horton**. They are very definitely tied together. Diabetes can be an insidious disease. We have an estimated 12 million people with diabetes in the United States today, and perhaps one-half of those people have the disease and do not even know it yet. Diabetes leads to long-term disabilities and damage to many tissue systems. It is the leading cause of new onset blindness in the United States today. It is the leading cause of the development of end-stage renal disease, and accounts for 25 percent to 30 percent of people who are currently in kidney dialysis programs. It leads to damage to the nervous system, which results in numbness and tingling and ulcerations.

And it leads to hardening of the arteries, if you will, which can cause either heart disease or strokes, or peripheral vascular disease. Diabetes is the major underlying cause for nontraumatic amputations in the United States today.

So in all of these areas diabetes is an underlying condition that leads to damage to these various tissues. Our recommendation for emphasis in cardiovascular disease is to try and understand better the linkage between how diabetes results in this hardening of the arteries, with the development of either peripheral vascular disease, amputations, heart disease or strokes.

Senator **Adams**. Thank you very much, Doctor, for your very informative testimony.

STATEMENT OF HAROLD J. FALLON, CHAIRMAN, NATIONAL DIGESTIVE DISEASES ADVISORY BOARD

Senator **Adams**. Our next witness is Dr. Harold Fallon, chairman of the National Digestive Diseases Advisory Board.

Dr. **Fallon**. Thank you, Senator Adams. I appreciate the opportunity to speak with the group today.

I am Dr. Harold Fallon, chairman of the department of internal medicine at the Medical College of Virginia and also chairman of the National Digestive Diseases Advisory Board. We have submitted written testimony, and I would appreciate your including that in the record.

Senator **Adams**. Without objection, your full statement will be included in the record.

Dr. **Fallon**. As you know, digestive diseases include a group of common disorders such as peptic ulcer disease, gallstones, cirrhosis, and hepatitis, but also cancer of the colon and intestinal diseases and a long list of less pronounceable disorders that I will not review.

But the Digestive Disease Advisory Board has been concerned with a number of issues, none greater than our concern with the current level of funding of research in this field, primarily through the National Institutes of Health. Although there has been significant progress in the last decade or two in research in these diseases, the relative discrepancy between the increasing cost of biomedical research and the level of funding of the NIH suggests that that progress will shortly be stalled.

In order to maintain the current level of grants, in this particular field at 50 percent of what it was only 3 years ago, there has been reduction in the funding of individual grants, reduction in training of new researchers and drastic reduction in the funding for digestive disease centers, a congressionally mandated program. Despite all this, the time is promising for further clinical investigation, and this is what has concerned us. We would like to make three specific recommendations.

First is that the National Institutes of Health be funded next year at the level recommended by the ad hoc group on medical research funding. All of research is applicable to other areas of biomedical interest, and therefore general funding is necessary.

In addition, specifically for digestive diseases we recommend an increase in the funding of the NIDDK to at least $736 million in 1991 to restore the level of grants to the 40-percent level, which is approximately what it was only 3 years ago, and to increase the funding of centers to the minimum expected by Congress several years ago.

We would like to recommend one additional item, and that is the support of clinical trials in digestive diseases in 1991. The level is $7.5 million. It is an appropriate time to translate some of the basic research findings into improved clinical care, and there are four areas that this is especially important to in our area of interest: peptic ulcer disease, treatment of gallstones, inflammatory bowel disease, and primary biliary cirrhosis.

PREPARED STATEMENT

Just to review briefly since primary biliary cirrhosis may be a disorder that is not too familiar to you. It is an increasingly common and severe disease, especially of women in the prime years of their life, often leading to death or liver transplantation. New leads in immunologic basis of this disorder and the effects of certain toxic compounds that accumulate in the blood suggest that a clinical trial on a national basis to investigate new therapies may reduce the death rate, the morbidity and perhaps reduce the need for transplantation. Only the NIH really has the capacity to appropriately run these trials, and they need funding to do so. Thank you.

[The statement follows:]

STATEMENT OF HAROLD J. FALLON

I am Dr. Harold J. Fallon, Chairman, Department of Medicine, Medical College of Virginia, and Chairman of the National Digestive Diseases Advisory Board. The Board was established by Congress to monitor the implementation of the national long-range plan that was developed by the National Commission on Digestive Diseases.

The numerous disorders known collectively as digestive diseases include serious and potentially life-threatening illnesses such as cirrhosis of the liver, inflammatory bowel disease, hepatitis, cancer, ulcers, and gallstones. These acute and chronic disorders have one common element--they affect the digestive tract, which includes the esophagus, stomach, liver, pancreas, small and large intestines, and anorectum. Digestive diseases are responsible for approximately 13 percent of all admissions to general hospitals in the United States and 10 percent of all surgical procedures. They affect more than one-half of the U.S. population at some time during their lives.

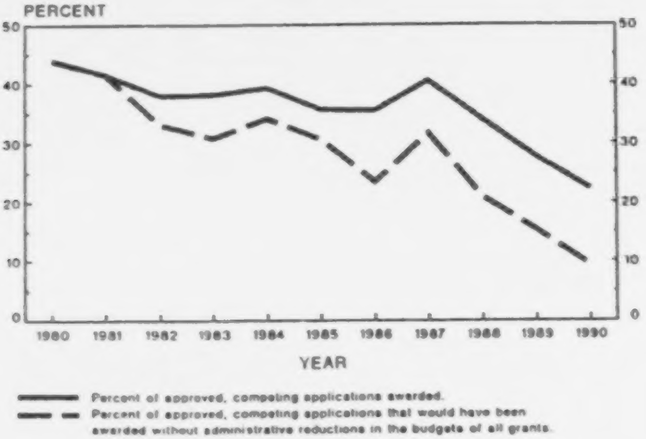
Digestive Diseases Research, NIDDK

The Board is greatly concerned about the inadequate appropriations for digestive diseases research. In the year following completion of the Commission's long-range plan, the Congress provided additional funds to begin implementation of the recommendations. However, this initial impetus has not been sustained and the percentage of approved applications for research that can be awarded has declined precipitously. At the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), the award rate has fallen from 44 percent 10 years ago to 22 percent in FY 1990.

In addition, the budgets of all awarded grants are now reduced below the amounts approved by the scientific review committees. The size of this reduction reached 12 percent in 1990. If these reductions had not been implemented, the actual award rates for competing applications would have been only 9.3 percent in 1990 (see Figure 1). Figure 1 provides a striking perspective of the fiscal status of biomedical research programs at NIDDK.

FIGURE 1

AWARD RATIO FOR COMPETING RESEARCH APPLICATIONS
NIDDK, 1980-1990



The failure of Federal appropriations to keep pace with new research opportunities and with the rising cost of biomedical research is seriously affecting established research programs and deterring future scientists from entering research careers. The Board believes that at least 40 percent of approved individual research grant applications at NIDDK should be funded at budget levels approved by the scientific review committees. This increased level of funding will lead to an increase in our knowledge of digestive diseases and will facilitate the prevention, detection, and treatment of these diseases.

The Board recommends that Congress and the administration provide $525 million in FY 1991 for research project grants in NIDDK to support 40 percent of approved projects at recommended budget levels.

Carefully controlled clinical trials are an essential component of the research continuum that leads from the laboratory to patient treatment. Without clinical trials, many research questions remain unanswered, and potential treatments are not evaluated. Last year, the Board recommended that additional funds be appropriated to NIDDK to initiate new clinical trials. The Senate Committee on Appropriations thereafter requested that the

NIDDK thoroughly examine the need and potential for clinical trials in digestive diseases and report to the Committee.

The Institute's report to the Committee highlighted four areas considered to be the most compelling due to public health needs, scientific opportunity, and/or technical feasibility: primary biliary cirrhosis, inflammatory bowel disease, gallstones, and peptic ulcers. The Institute has estimated the first-year costs of trials in these four areas to be approximately $7.5 million. These costs will increase in subsequent years as each trial proceeds through planning, feasibility, and full-scale phases. Total funding, over a 5- to 7-year period, is estimated at $36.5 million, plus the cost of at least two additional staff members required to administer the trials.

These trials cannot be initiated within existing resources without severely affecting the current investigator-initiated research grants described above. Therefore, additional funds must be appropriated to NIDDK.

> **The Board recommends that an additional $7.5 million be appropriated to NIDDK in FY 1991 to initiate new clinical trials in digestive diseases.**

In addition to the activities cited above, the NIDDK also supports Digestive Diseases Research Centers and Clinical Nutrition Research Units. These centers are funded far below recommended levels, seriously impairing their activities. The Institute's research training and intramural research programs also require increased support.

> **The Board recommends that the total appropriation for NIDDK be increased to $736 million in FY 1991.**

Prevention of Hepatitis B-Associated Liver Disease, CDC

Hepatitis B is a major public health problem. Each year, 5,000 to 6,000 deaths occur from acute and chronic hepatitis B-associated liver disease. Next to alcohol abuse, hepatitis B appears to be the major cause of cirrhosis of the liver and liver cancer. Although a highly effective vaccine against hepatitis B became available in 1982, the incidence of the disease continues to rise because the vaccine is not reaching those individuals who are at greatest risk of infection.

Recently, the Board reviewed the status of efforts to control hepatitis B. The Board also received a report from the Centers for Disease Control (CDC) that provided a summary of alternative strategies for controlling the disease. The Board subsequently concluded that a comprehensive national public health program should be initiated to eliminate hepatitis B transmission. This program should include universal immunization of children. The Board has transmitted this recommendation directly to the Secretary of Health and Human Services and to the Immunization Practices Advisory Committee that advises the Public Health Service. Additional funds are required for this initiative.

The Board recommends that Congress and the administration provide additional funds to CDC by FY 1991 to implement a national program to eliminate transmission of the hepatitis B virus in the United States.

HEPATITIS B

Senator ADAMS. Doctor, on the last page of your testimony, you indicate that hepatitis B is very often fatal and a major cause of cirrhosis of the liver and liver cancer, and that there is a vaccine for it. Well, first, you have a substantial statement here on transmission and immunization of children. How is hepatitis B transmitted?

Dr. FALLON. Hepatitis B is transmitted by several routes. It is primarily a blood-borne infection. Transmission by blood transfusion has been virtually eliminated in this country. The major route of transmission is thought to be by sexual transmission very much like AIDS. It is a much more infectious disease than AIDS, but it is transmitted very much in the same manner.

Our recommendations in this particular arena address the vaccine policies of the CDC. We do have available a vaccine that can prevent this disease. There is no need in the United States for individuals to succumb to this disease and to develop hepatic cellular carcinoma.

Vaccine policies of the CDC should be developed to allow childhood immunization, with perhaps subsequent booster shots at some time as yet unknown and unspecified. It is an extremely safe vaccine, reasonably inexpensive. The fruits of NIH-supported investigation are there. We need to implement those findings if we are to eradicate one of the major causes of cirrhosis and liver cancer in this country.

Senator **Adams**. Do you have a cost for that program?

Dr. **Fallon**. No; we do not. That is a difficult issue to deal with. CDC does have estimates. The problem is that if one immunizes health care workers, which is the current policy, or high-risk populations, the cost of a vaccine is considerably higher than if you recommend it for a much wider spectrum of the American population.

But for an investment of, say, $100 million or $150 million, the overall eradication of a disease that has very much more financial implications is possible. But the exact cost of a national immunization program has not been established, at least not in any testimony provided to our board.

Senator **Adams**. Thank you very much. We appreciate your testimony.

STATEMENT OF GEORGE P. FILO, CHAIRMAN, GOVERNMENT RELATIONS COMMITTEE, JUVENILE DIABETES FOUNDATION

Senator **Adams**. Our next witness is George P. Filo, chairman of the Government Relations Committee of the Juvenile Diabetes Foundation.

Mr. **Filo**. Thank you, Senator Adams.

On behalf of the Juvenile Diabetes Foundation International, I appreciate this opportunity to present our views concerning fiscal year 1991 appropriations for the National Institutes of Health. My name is George Filo, and I am chairman of JDS Government Relations Committee and a member of the board of directors, and I have been an insulin-dependent diabetic for 23 years.

Mr. Chairman, 15 years ago, there was no Federal diabetes program to speak of, a mere trickle of funding and virtually no infrastructure. However, commencing with a 1975 long-range plan to combat diabetes, this committee heeded our call and provided funds for diabetes research, over $2.5 billion since 1975, and the investment you have made has paid enormous dividends. Unlike 15 years ago, we now have a reasonable basis for being optimistic about a cure and prevention of this insidious and debilitating disease.

With Federal research dollars, scientists have made it possible for the majority of diabetic women to have normal pregnancies. With Federal research dollars, millions of diabetics are benefitting from new drugs and new ways of taking insulin. Because of Federal research dollars, diabetics can now avail themselves of laser photocoagulation therapy to treat diabetic retinopathy and significantly reduce the risk of blindness.

More, however, must be done. Despite the potential for progress in diabetes research, the current budgetary climate has brought the medical research enterprise to the brink of crisis. The signs are everywhere. Fewer and fewer competing research projects are awarded grants, and when they are, they receive only partial funding.

And increasing numbers of scientists, especially young ones, are discouraged by funding instability, from entering or continuing medical research careers. We must make a determination as to whether we follow the path of retrenchment or the path toward capitalizing on scientific opportunity. For us the choice is clear.

JDF recommends that Congress appropriate, at a minimum, $9.2 billion for NIH in fiscal year 1991, as recommended by the ad hoc group for medical research funding. With an ample appropriation to the NIDDK, diabetes research appropriations can be pursued.

Mr. Chairman, as others last week testified, a particularly exciting area of diabetes research involves the search for the genes responsible for the onset of diabetes and its complications. Achievement of this goal could have a dramatic effect on research into the cause and cure of diabetes, just as the recent cloning and sequencing of the gene responsible for cystic fibrosis represents a major breakthrough in the war on that disease.

While NIDDK has attempted to stimulate further research in genetics, current resources are simply insufficient to seize on research opportunities in this cutting-edge area of diabetes research.

PREPARED STATEMENT

Mr. Chairman, this committee made history in helping to create the Federal diabetes effort. The research which you have funded over the past decade, has yielded huge dividends in terms of reduced diabetic mortality and morbidity and reduced health care expenditures. By the year 2000, I am hopeful that we will feel a great sense of reward because the research advances funded by Congress today will have yielded a cure for diabetes.

Thank you for your past and continued support.

[The statement follows:]

STATEMENT OF GEORGE P. FILO

Summary of Recommendations:

The Juvenile Diabetes Foundation International recommends that, for FY 1991 the National Institutes of Health ("NIH") be appropriated, at a minimum, $9.2 billion (a 22% increase over the FY 1990 funding level). The National Institute of Diabetes, Digestive and Kidney Diseases ("NIDDK") should be appropriated $808 million; the National Heart, Lung, and Blood Institute ("NHLBI") - $1.3 billion; the National Eye Institute ("NEI") - $288.6 million; the National Institute of Child Health and Human Development ("NICHD") - $540.3 million; the National Institute of Neurological Disorders and Stroke ("NINDS") - $91.4 million; the National Institute of Allergy and Infectious Diseases ("NIAID") - $1 billion; National Institute on Aging ("NIA") - $292.1 million; National Institute of Dental Research ("NIDR") - $ 210 million; National Cancer Institute ("NCI") - $2 billion; National Institute of General Medical Science ("NIGMS") - $868.7 million; and the Division of Research Resources ("DRR") - $411.3 million.

We also recommend that $6 million be appropriated for the Centers for Disease Control's State Diabetes Control Projects.

The Juvenile Diabetes Foundation International ("JDF") appreciates this opportunity to present its views regarding FY 1991 appropriations for the National Institutes of Health ("NIH") and other federal diabetes programs. JDF is an international voluntary health organization of over 160 chapters and affiliates throughout the U.S. and the world dedicated to furthering research in diabetes and improving the quality of life of persons with diabetes. This year JDF is celebrating its 20th anniversary, and we have established as our theme the "Decade of the Cure". We challenge Congress to join us in this goal.

FIFTEEN YEARS OF PROGRESS.

Fifteen years ago, the federal government embarked in earnest to implement the National Diabetes Advisory Board's ("NDAB") first Long Range Plan to Combat Diabetes (the "Long Range Plan"). In 1975, there was no federal diabetes initiative to speak of -- little funding and no infrastructure. The biomedical research community's commitment to diabetes research could be characterized as benign neglect of a disease which wreaked havoc upon virtually every body system -- the eyes, the heart, the kidney, the nervous system.

DIABETES RESEARCH BREAKTHROUGHS.

Commencing with the publication of the 1975 Long Range Plan, you heeded our call and provided funds for diabetes research -- over $2 billion since 1975. The investment you have made has paid off in enormous dividends. Unlike fifteen years ago, we now have a reasonable basis for being optimistic about a cure and prevention of this insidious disease.

The NDAB's 1987 revised Long Range Plan chronicles the remarkable research progress made in just fifteen years, all advances coming as the result of federal research dollars. These include: identification of genetic markers of diabetes;

production of human insulin by recombinant DNA technology; laser photocoagulation to treat diabetic retinopathy and reduce the risk of blindness; improved methods for measuring and regulating blood sugar in diabetics, like home glucose monitors and the insulin pump; and clinical trials in which human subjects are undergoing pancreatic islet cell transplantation.

AT THE CROSSROADS: A CRISIS YET UNRESOLVED.

Despite the cause for optimism in diabetes research, the specter of diabetes and its devastating complications remains pervasive. In the United States, diabetes is the third leading cause of death by disease; diabetes is the leading cause of new cases of adult blindness; diabetes accounts for 30 percent of new cases of end stage renal disease ("ESRD"), and is projected to account for 50 percent of these cases by the year 2000; and heart disease is twice as common and more often fatal in diabetics than in the general population.

Diabetes also has staggering economic dimensions. A conservative estimate of the total annual direct costs attributable to diabetes is $20 billion. Annual savings of $454 million in the national costs of care for the blind can be realized through the use of laser therapy in advanced cases of diabetic retinopathy. The annual hospital cost for the over 40,000 amputations related to diabetes exceeds $302 million.

A TIME FOR RECOMMITMENT: JDF's FY 1991 APPROPRIATIONS RECOMMENDATIONS.

Despite Congress' strong support, the current budgetary climate has brought the medical research enterprise to the brink of crisis. While our nation has for many years been the world leader in medical research, there are increasing signs of stress in the system which together suggest that the infrastructure is in steady decline. The signs are everywhere: fewer and fewer new and competing research projects are awarded grants, and when they are, they receive only partial funding; increasing numbers of scientists -- especially young ones -- are discouraged by funding instability from entering or continuing medical research careers; reduced funding for training of basic scientists and clinical researchers; and growing deterioration of federally-supported laboratory facilities and equipment. Add to these ominous signs the frightening lack of student interest and proficiency in the sciences, and we have the makings of a genuine crisis.

Administration Budget. While JDF acknowledges that the Administration has proposed a modest increase of 4.7 percent for NIH in FY 1991, we are disturbed that this budget would not even allow the NIH to support its current level of effort, falling $400 million short of the NIH estimate of current services.

JDF's Recommendations. As we approach a major turning point in biomedical research in general and diabetes research in particular, we must make a determination as to whether we follow the path of retrenchment or the path towards capitalizing on scientific opportunity. For us, the choice is clear. JDF recommends that Congress appropriate, at a minimum, $9.2 billion for NIH in FY 1991, as recommended by the Ad Hoc Group for Medical Research Funding (the "Ad Hoc Group"). This request represents a 22 percent increase in the NIH budget.

Under this proposed budget, NIH could fund approximately 30 percent of approved research grant applications, a step towards ultimate achievement of an award rate of 50 percent. The Ad Hoc Group proposal would also fully fund existing research centers and support approximately 20 centers. JDF firmly believes that all research grants should be awarded at study section-recommended levels and not be subject to "downward negotiation", which threatens to compromise the quality and integrity of NIH-supported research. While we support the Ad Hoc Group recommendation for NIH, we feel compelled to point out that, in order to capitalize fully on current research opportunities, NIH would need funding of approximately $11.7 billion. The difference between this level and current funding for NIH underscores the numerous opportunities that are currently being lost.

DIABETES-SPECIFIC INITIATIVES.

Our goal should be nothing short of curing diabetes within the next decade by providing the resources for a comprehensive frontal attack on the disease, one embodying continuing support for basic and applied research and the translation of available research information into clinical care to reduce the burden that diabetes places on the nation.

The Search for the Diabetes Genes. A particularly exciting area of diabetes research which is receiving increased attention within the scientific community involves the search for the genes which are responsible for the onset of diabetes and its complications. Achievement of this goal could have a dramatic effect on research into the cause and cure of diabetes, just as the recent cloning and sequencing of the gene responsible for cystic fibrosis represents a major breakthrough in the war on that disease. While the task with regard to diabetes is more complex, there is significant cause for hope. A substantial amount of genetics research into diabetes has been conducted in the past several years, and has led, for example, to the dramatic discovery of a diabetes susceptibility gene in Type I diabetes. This gene appears to be necessary, but not completely sufficient, to cause the disease. In animal models, it appears that additional genes are involved, but no other gene has yet been identified in humans. With regard to Type II diabetes, the clustering of prevalence among certain distinct minority groups, along with studies of families in animal models, further points to the genetic nature of this disease. We do not yet know which genes are involved, but the approaches that will be necessary to identify them are clear.

JDF has identified the last decade of this century as the "Decade of the Cure". If we are to achieve this goal, a major assault must be made on identification of the relevant genes, utilizing current technologies and developing new ones as the research progresses. While NIDDK has, to the extent possible, attempted to stimulate further research in genetics and molecular biology, current resources are simply insufficient to capitalize on research opportunities in this burgeoning area of diabetes research. We know that the research tools exist with which to finally conquer this insidious disease. Accordingly, JDF strongly urges this Committee to provide additional funding to NIDDK for enhanced research into identification of the diabetes genes.

Diabetic Kidney Disease. Kidney disease is a significant cause of death and disability for individuals with diabetes and is a monumental drain on the American economy. Studies during the past decade have demonstrated that some of the early changes in kidney function can be reversed or prevented by strict control of blood glucose levels and by treatment of kidney infections and hypertension. JDF applauds this Subcommittee's and Congress' decision last year to provide additional funding to NIDDK for enhanced research into diabetes-related kidney disease. The Institute is currently soliciting research proposals in this area.

Access to Research Resources. The 1987 Long Range Plan makes clear the need for both human and animal tissue in conducting diabetes research.

CONCLUSION.

This Committee made history in helping to create the National Commission on Diabetes, whose Long Range Plan became the foundation for the federal diabetes effort. The research which you have funded over the past decade has built upon this foundation and has yielded huge dividends in terms of reduced diabetic mortality and morbidity and reduced health care expenditures.

Ten years from now, will we feel a great sense of reward, because the research advances funded by Congress today have yielded a cure for diabetes? Or will we look back over a long line of opportunities foregone, and a diabetes program atrophying for want of federal support? We hope that, once again, this Committee will do what you know in your hearts is right.

DIABETES GENE

Senator **Adams**. Thank you. What amount of additional funding do you recommend for enhanced research and identification of the diabetes genes?

Mr. **Filo**. Well, for next year's initiative or the next fiscal year, 1991, we would look in the area of between $5 and $10 million.

Senator **Adams**. Thank you very much. We appreciate your testimony, Mr. Filo.

STATEMENT OF D. MARTIN CARTER, PROFESSOR AND SENIOR PHYSICIAN, ROCKEFELLER UNIVERSITY

Senator **Adams**. Our next witness is Dr. D. Martin Carter, professor and senior physician of Rockefeller University.

Dr. **Carter**. Good morning, Senator, and thank you. I have given written testimony that I hope you will enter into the record so that I can summarize my comments at this time.

Senator **Adams**. Without objection, your full statement will appear in the record as though given and you may summarize.

Dr. **Carter**. Thank you. I am a clinical investigator and an academic dermatologist at the Rockefeller University in New York. But today I am here as an advocate of those people who have one of the rare diseases, one of the 10 to 20 million Americans who have one of the rare or they are often called orphan diseases, which are defined by law as those which affect less than 200,000 Americans, or for those that the development of new drugs is thought to be nonprofitable to industry. The people who have one of these diseases often have medical costs of more than $100,000 per year and therefore they are of great importance to our country's economy, as well as the loss of productivity to the individuals and the individual pain and suffering they experience.

One year ago, the National Commission on Orphan Diseases that was authorized by the Government, asked that a number of steps be taken to improve the plight of these individuals. One of these recommendations was that rare disease registries be established to help to deal with the collection of data, biological data, the banking of cellular and other biological material, to institute clinical trials, to understand the course of disease. There have been many of these that have been operating over the years. They have primarily been operated under private resources, not by governmental ones. There have been governmental examples, however, of the Huntington's disease registry that was recommended by the Huntington's Commission and has led to great progress in this devastating neurologic disease, the EB registry, which deals with a rare, blistering skin disease has been authorized by the NIAMS and in its brief years of operation, has already identified more than 1,200 individuals with this disease whose cooperation has been useful.

There is a registry that has been recommended by the National Heart, Lung, and Blood Institute, dealing with Fanconi anemia, which has as yet, not had any money, and there is another registry that has been recommended by one of the rare kidney diseases to provide molecular biological information to help to deal with these conditions.

It is very important that these steps be taken. It is our belief that in order to solve these problems, we must have interinstitutional groupings of investigators across the country in order to have enough material to try to answer the important questions. These are orphan diseases; they need to be adopted. One of the ways in which this adoption can take place is with the help of this committee, which in the past, has recognized the importance, not only to the individuals who have them, but to the advancing of biological knowledge on disease in general.

One recommendation has been that at least one registry be sponsored by each of the institutes. The cost of this would probably be in the range of $2 million each, and is a reasonable expectation.

PREPARED STATEMENT

I have one thing I would like to add. You asked one of the other investigators earlier on—I do not mean investigator—I mean a witness, about the relative investment of the United States in research compared to other countries, and in Science magazine last month, the issue of February 16, there is a very nice news report on this which does not show our country to be in a very favorable position with respect to Japan and West Germany.

Senator **Adams**. Thank you very much, Doctor.

[The statement follows:]

STATEMENT OF D. MARTIN CARTER

My name is Dr. Martin Carter. A clinical investigator and academic dermatologist at The Rockefeller University Hospital in New York City, I am here as an advocate for clinical research, which in my view offers the only possibility for alleviating the suffering of the millions of Americans who suffer from one of the 5000 "orphan" or rare diseases. An orphan disease is defined by law as one which afflicts fewer than 200,000 Americans and for which the development of new drugs is unlikely to be profitable to industry. The diseases are thus "orphans" and must be adopted by investigators if the problems they create are to be solved.

A year ago the National Commission on Orphan Diseases, of which I was a member for two years, submitted its report to Congress. I am here today to speak about one of the Commission's recommendations: the need for our Government to support the establishment and maintenance of registries -- data bases for rare disease research. To understand and provide effective treatment for these, medical scientists require enough patient-derived information and biological material to conduct specific types of experiments. The resources which can provide such information are registries of biological, medical and epidemiological information, and cell banks and other repository systems for storage of human tissue.

Registries already exist for a number of rare diseases, such as epidermolysis bullosa, Fanconi anemia, Bloom syndrome, progeria, Tourette syndrome, Huntington disease, neurofibromatosis, and xeroderma pigmentosum but their futures are uncertain. Most have been funded solely through private sources, and those which have received federal support are unsure whether support will be maintained. These registries have made a major contribution to elucidating the natural course of rare diseases; to trials of possible drug treatments; and even to mapping the genes responsible. More such registries are needed -- but in the present climate, despite the recommendations of the National Commission, they will not be provided without specific recommmendations that they be established. A reasonable goal would be for each NIH institute to support at least one such project.

Working through the resources of the General Clinical Research Centers (GCRCs) -- themselves invaluable but under-appreciated facilities for conducting clinical research and improving the health of American citizens -- rare disease registries can be highly effective and cost-efficient. Using GCRC Core Laboratory resources, the specific biochemical, histopathological or cytogenetic screening tests that are required for unambiguous diagnoses can be performed.

Registries stimulate research and improve patient management. Several years ago the National Huntington Disease Commission recommended, among other things, that a Huntington Disease Registry be established. This was done, and progress has been made in understanding this devastating heritable neurological disease. Geographically dispersed research groups have used Registry pedigrees, cellular material and other data. Competing scientists who comprise The Huntington's Disease Collaborative Research Group have engaged in cooperative projects. The exciting story of the mapping of the Huntington gene continues. Even as we meet here new complexities in mapping the human genome are being revealed.

A National Epidermolysis Bullosa (EB) Registry was authorized four years ago by the National Institute of Arthritis, and Musculoskeletal and Skin Diseases to study people with a heritable disease which makes their skin subject to easy blistering and chronic wounding. Already more than twelve hundred persons with this rare skin disease have been registered and are being followed at one or another of the four clinical centers in New York, Washington, California and Alabama. The EB Registry has stimulated basic research by several laboratories on the biology of the basement membrane zone of normal skin and in EB. In addition, cooperative clinical and laboratory studies have been initiated on such varied subjects as wound healing, cellular grafting, artificial skin, skin cancer, and gene-mapping. Publications by Registry collaborators have dealt with diagnostic criteria, clinical manifestations of EB, corrective surgical intervention and a variety of other topics.

Autosomal recessive polycystic kidney disease (ARPKD) is a rare genetic disorder that produces a combination of kidney cyst formation and bile duct abnormalities in affected children. Most ARPKD patients are infants, many of whom die due to abnormalities of lung development, renal failure and severe hypertension. Although the pathogenic mechanisms causing the disease are unknown, research is being conducted in a number of laboratories. In addition, kidney transplants can be provided to very young children with severe chronic renal failure. Many pediatric nephrologists believe that new approaches to the care and pathogenesis of ARPKD should be undertaken by a national multicenter cooperative effort, which should include study of both the therapy and the course of disease and also collection of a large number of samples for molecular genetic analysis. Central to such an effort would be construction of a data bank of cellular material for DNA analysis.

The National Heart, Lung and Blood Institute recently developed a request for a proposal to establish a National Fanconi Anemia (FA) Registry. Funds for this project may not be forthcoming, although the value of the project has been widely acknowledged. As with other rare disease registries, this would become a central repository for clinical, hematologic and genetic data on patients with Fanconi anemia and would enhance basic and clinical research on this disease. The constitutional, or genetic, aplastic anemias comprise more than 25 percent of all childhood bone marrow aplasia. The most common of these is Fanconi anemia (FA), an autosomal recessive disorder characterized by progressive pancytopenia, diverse congenital abnormalities and increased cancer risk. Research on this rare disease may further our understanding of the etiology of certain cancers and birth defects.

The National FA Registry would supplant the International Fanconi Anemia Registry (IFAR) -- established at The Rockefeller University in 1982 from private resources which are no longer available. Cases have been referred by voluntary physician reporting based upon clinical manifestations, and the diagnosis of FA is confirmed by testing for chromosomal fragility using a specific test for hypersensitivity to DNA crosslinking by diepoxybutane (DEB). The IFAR data have already provided important information about the clinical diversity and natural course of the disorder, its mode of inheritance, and the value of therapeutic trials. Furthermore, a good start has been made on mapping the FA gene using DNA from blood of IFAR registrants.

These examples of Rare Disease Registries illustrate not only their diversity -- depending upon the specific nature of the patients and the type of data needed to diagnose and study their condition -- but also the similarities of these Registries in terms of the personnel needed and the ideal sites for their location. The National Commission on Orphan Diseases recommended that each NIH institute fund at least one such Registry. The NIH should carefully select the conditions for which Registries will be established, taking into consideration the state of scientific expertise in the relevant fields, and put these Registries in sites where GCRCs already exist -- thus assuring patients who participate that they will receive some clinical services in addition to advancing research knowledge. These things will happen only if the Congress specifically directs that they should. If you do authorize this step, then substantive progress can be made in solving the problems of the millions of Americans who are victims of Orphan Diseases.

Opinions expressed in this report are those of Dr. Carter who accepts sole responsibility for them. However, information was gathered from a number of medical scientists who are authorities in clinical research on rare diseases. These people include:

Arleen Auerbach, PhD, Rockefeller University; Eugene Bauer, MD, Stanford University; Dorothea Caldwell-Brown, NP MPH, Rockefeller University; Louis J. Elsas III, MD, Emory University; H. William Harris, Jr., MD, PhD, Harvard Medical School; Andrew Lin, MD, Rockefeller University; Abbey Meyers, National Organization of Rare Diseases; Arlene Pessar, RN, Dystrophic Epidermolysis Bullosa Research Association; Lee Schacht, PhD, Minnesota Health Department.

STATEMENT OF CHARLES B. CARPENTER, CHAIRMAN, THE INTERSOCIETY COUNCIL FOR RESEARCH OF THE KIDNEY AND URINARY TRACT

Senator Adams. Our next witness will be Dr. Charles Carpenter, and the committee will be in recess for 1 minute.

[A brief recess was taken.]

Senator D'Amato. My apologies, Dr. Carpenter. Welcome to the committee and we are pleased to have you with us this morning. This is Dr. Charles B. Carpenter, chairman of the Intersociety Council for Research of the Kidney and Urinary Tract, and I felt that you were an appropriate time for me to leave.

Please proceed, Doctor.

Dr. Carpenter. I will avoid any further comment about that.

Senator Adams. I know, let us leave that one right where it is.

Dr. Carpenter. My name is Charles Carpenter, and I am a professor of medicine at Harvard Medical School and chairman of this intersociety council, which represents the fields of neurology, nephrology, and transplantation. There are 10 societies and associations in the group. Some of them will be presenting separate testimony to this committee during the course of this day.

What I intend to do, in addition to the written testimony which has been submitted, and I request that it be put into the permanent record——

Senator ADAMS. Without objection, the full statement will appear in the record as though given, Doctor.

Dr. CARPENTER. I will attempt to summarize some of the main overarching problems that confront our field. There are about 13 million people in the United States that have diseases of the kidney or urinary tract. The costs are in the vicinity of $50 billion a year for total health care expenditures.

Some examples are the end-stage renal disease program which is consuming approximately $4 billion a year for dialysis and transplantation. You may also be interested to know that diseases of the prostate alone, account for about 3 billion dollars' worth of health care expenditures.

And we wish to point out that as the population ages, there probably will be considerable worsening of this burden, particularly as problems in urinary incontinence and cancers of prostate and bladder accumulate in the population.

There are, of course, hundreds of different diseases of this tract, and we are concerned, not about just the specific, high-cost items, but for the field as a whole, and particularly about our ability to recruit and sustain young investigators in the broad field of molecular biology, as it now is impinging on the problems of the urinary tract, to sustain this in the future.

This year, the Kidney and Neurologic Diseases Advisory Board report has appeared. This was a committee that was appointed by the Secretary of DHHS, and this is an extraordinarily detailed document that gives all of the background for our understanding now of the extent of these problems in the United States and a long-term plan, a 10-year plan, more or less, for implementation to solve some of these problems. And I simply want to point out where we might begin in the view of our council.

We note that the ad hoc committee for research funding, in noting the problem with underfunding and the declining funding levels for young investigators, the future of our field, have pointed specifically to increasing investigator-initiated grant fundings, and to not only the full funding of existing centers in various diseases, but also to the establishment of additional centers. This, indeed, is one of the major recommendations of the Kidney, Urology Disease Advisory Board. And we, therefore, wish to specifically recommend that there be six new NIDDK O'Brien Centers added to the existing number. This would be at an annually expenditure of $6 million at full funding.

PREPARED STATEMENT

We would also add $1.2 million to bring the existing centers up to the full funding level, and would also recommend that strong consideration be given to add some training positions to these centers. This would be particularly helpful in the fields of pediatric nephrology and in neurology, which are very much underserved, and are struggling to recruit and train adequate numbers of new individuals.

Thank you very much.

[The statement follows:]

STATEMENT OF CHARLES B. CARPENTER

I am Charles B. Carpenter, M.D., Professor of Medicine at Harvard Medical School and the Brigham and Womens' Hospital in Boston, and Chairman of the Intersociety Council for Research of the Kidney and Urinary Tract. I am presenting this testimony on behalf of the Intersociety Council which represents the American Association of Genitourinary Surgeons, the American Society of Nephrology, the American Society of Pediatric Nephrology, the American Society of Transplant Physicians, the American Society of Transplant Surgeons, the American Urological Association, the National Kidney Foundation, the Polycystic Kidney Research Foundation, the Renal Physicians Association, the and the Council on Kidney of the American Heart Association.

Mr. Chairman, each year the Intersociety Council brings before you the major concerns of the kidney and urology community regarding needs in research. Approximately 13 million people nationwide are afflicted by diseases of the kidney and urinary tract, and more than 8% of the total national health expenditure is being expended in the care of people with these diseases. The Medicare costs for patients dependent upon dialysis or kidney transplantation exceeded $3.4 billion in 1987. Diseases of the prostate cost in the vicinity of $3 billion annually. Problems of urinary incontinence and cancer of the prostate and urinary bladder are expected to increase the health care burden as our population ages. Diseases of the kidney and urinary tract number in the hundreds, and continuing research is needed on a broad front. We need to attract talented young investigators to devote their careers to solving these problems The promise, for example, in application of new developments in molecular biology to understanding and treatment of these diseases is great.

This past year the National Kidney and Urologic Diseases

Advisory Board (KUDAB), appointed by the Secretary of the Department of Health and Human Services, has completed its work, and the report, "1990 Long Range Plan -- Window on the 21st Century," has just been presented. It contains an extraordinary analysis of the state-of-the-art and remaining problems in our field. The Intersociety Council and its member organizations are in strong support of its findings and of its recommendations which provide a realistic plan if significant progress is to be made in reducing the burdens of kidney and urologic diseases on the lives of all our citizens.

The total budget for kidney and urologic research in the NIH is 2.3% of the total NIH budget. Approximately 3/4 of this is in the NIDDK. Representatives of the member societies in the Intersociety Council will present separate testimonies with details of specific areas of concern to the kidney and urology community. In addition, the NIDDK is submitting to the Congress a report on the status of urologic research training. (Copy Attached) My testimony focuses on the major issues affecting the entire field of kidney and urologic disease research.

We acknowledge that this is a time of severe budgetary constraint, and we share with the rest of the NIH community deep concern about the present state of declining funding opportunities for young investigators who indeed represent the entire future of biomedical research. In my Intersociety Council, I have heard testimony on the numbers of talented young scientists who are electing to leave kidney and urinary tract research for clinical careers because they see the doors closing on possibilities for research support.

In last year's testimony, we noted the disproportionate fall-off in funding levels for investigator-initiated grants in kidney and urologic research, in comparison with other branches within the NIDDK. In addition, a special initiative in kidney disease and diabetes mellitus (KDDM), a major cause of end stage renal disease (ESRD), had been going unfunded. The Congress responded with additional appropriations, and I am pleased to report that the result has been that the grant payline for kidney and urologic research has been maintained in the range of the NIH average, and that 10 KDDM grants of the highest quality have been awarded, with more applications under review.

We note that the AD Hoc Group for Medical Research Funding, in recognition of the growing negative impact of inadequate funding upon young investigators and the initiation of new initiatives, has recommended as their top priority full funding of approximately 30 percent of investigator-initiated research project grant applications in FY 1991, and also full funding of existing research centers addition of new centers. The independent assessment of the KUDAB developed similar priorities regarding the best means to sustain current research activity, and to capitalize on new research opportunities in diseases which until recently have been poorly understood. The Intersociety Council stands in strong support of the Ad Hoc Group's and the KUDAB's top priorities, which are to increase funds for investigator-initiated grants and for centers. Specifically, we support the top priorities of the KUDAB to expand the numbers of the George O'Brien Kidney Centers and to improve training and grant support for young investigators. With the existing centers, now in the third year of operation, the scientists conducting concerted research efforts in areas of hypertension, diabetes mellitus, obstructive and hereditary diseases of the urologic system, nutrition, immunology, and cellular injury are excited by the opportunities to generate needed answers in these areas. The KUDAB report has identified the following important areas in which research emphasis is sorely needed and which should provide the focus for new centers: impotence; kidney transplantation; glomerulonephritis and interstitial nephritis; polycystic kidney disease and other genetic diseases of the kidney and urinary tract; disorders of bladder structure and function; urinary tract stones and infections; kidney and urologic disorders in the newborn, child, and adolescent; and acute renal failure and nephro-toxins, including environmental toxicants and therapeutic drugs. As you can see, some of the needs in pediatrics and urology can be met by the center mechanism. We also recognize the importance of special emphasis on minoirties having a high rate of end stage renal disease, and look forward to the final development of NIDDK plans in this area during the coming year.

We now request that appropriation be made for addition of 6 new O'Brien Centers. At full funding level, these would cost $6 million annually, plus $1.2 million to bring the existing centers to full funding. Addition of training support to the centers would be an efficient way to develop new research leadership, especially in the underserved area of urology and pediatric nephrology.

I would like to express the appreciation from all the organizations which make up the Intersociety Council for Research of the Kidney and Urinary Tract for the interest shown by individual members, and by the subcommittee as a whole, in the scientific and humane enterprise known as biomedical research, now and in the future. This is a collaboration on behalf of all our citizens.

Senator **Adams**. Doctor, would you like to have that full report placed in our records or not? We would be pleased to receive it as part of the record, not necessarily printed in the hearing, but as something that we could refer to.

Dr. **Carpenter**. This is the final draft. There are some publishing—printing changes to be made that are minor, but there will very soon be the official product. I am holding here one of the first copies that was released by the committee for the use of the community.

Senator **Adams**. Would you submit a copy of that when it is completed?

Dr. **Carpenter**. Absolutely, we will get one to you as soon as we can.

Senator **Adams**. Thank you.

The second question that I have is, you are requesting six new O'Brien Centers. What specific type of research are you proposing for those six new centers?

Dr. **Carpenter**. The advisory board had a list of 10 or 12 areas that they earmarked, or I should not say earmarked, that is a different word here. They appointed to, as appropriate for center kind of activity and it is in the full report.

We have not chosen, ourselves, what the six centers should be. We are inclined to allow the NIH peer review process to make those judgments as to where the best quality research could be conducted, and what the precise topics would be. But, there are a large number of areas that cover pediatric nephrology, neurology, transplantation, and other areas involving minority populations and so forth, for which there is no center activity at all at the present.

Senator **Adams**. Thank you very much, Dr. Carpenter, for your excellent testimony.

STATEMENT OF E. DARRACOTT VAUGHAN, JR., AMERICAN UROLOGICAL ASSOCIATION, INC.

Senator **Adams**. Our next witness will be Dr. Darracott Vaughan, Jr., American Urological Association.

Dr. Vaughan, welcome.

Dr. **Vaughan**. Senator Adams, I thank you for the privilege of being here today, and I speak for the American Urological Association, which is our professional urology organization, the American Foundation of Urologic Disease, which is our lay organization. Also, I might say I was a deputy chairman of the advisory board, whose report Dr. Carpenter just showed you, and we certainly would very much like for you to have a copy of that report for this committee's use.

I also have a written statement which I would like to see accepted into the record.

Senator **Adams**. Without objection, your statement will appear in full in the record as though given.

Dr. **Vaughan**. To amplify a bit on what Dr. Carpenter just told you, I think the advisory board report, for the first time, gives us the scope and impact of urologic and kidney diseases. I think we were overwhelmed by finding that some 15 million or so Americans are involved in these diseases at an expense of $50 billion.

To be more specific in some urological entities, I was struck by the New York Times this morning, which had a large article about our concern for our elderly, and how we are going to care for an aging population. It turns out that 10 million elderly Americans suffer from urinary incontinence, and if we look at why our senior citizens are in nursing homes, many of them are in nursing homes because of incontinence. A pilot study, published in the New England Journal 1 year ago, show that one-third of those people have, as you said before, a reason that if technology were transferred appropriately, might correct their incontinence and get them out of the nursing homes. But benign prostatic hypertrophy and prostate cancer are becoming more prevalent in our aging population; 350,000 people, or to put it another way, one of every three or four of us sitting in this room will undergo a prostate operation if we do not put some more money into basic science to understand why the prostate normally grows as we get older, and prostate cancer is the leading cause of cancer, the most prevalent cancer in the male population now, and it has been for a number of years in the black population. So I would like to reiterate what Dr. Carpenter has said, and state that the vehicle of the O'Brien Centers gives us a mechanism by which to address these problems as well as other nephrology problems and transplantation problems. In addition, they gives us a site for training.

PREPARED STATEMENT

There has been a mandated study on training and neurology, and we have got data which will be submitted from Dr. Leroy Nyberg showing that we are training approximately one-half of the number of investigators we need at the present time. So, we have specific recommendations, again, for doubling the O'Brien Centers, for adding centers in urologic cancers, particularly prostatic cancer and to add training to the funding for these centers.

I thank you for your attention.

[The statement follows:]

STATEMENT OF E. DARRACOTT VAUGHAN, JR.

Mr. Chairman and Members of the Subcommittee:

I am E. Darracott Vaughan, Jr., M.D., Chairman of the Division of Urology at The New York Hospital-Cornell Medical Center and Deputy Chairman of the National Kidney and Urologic Diseases Advisory Board (NKUDAB). I am presenting this testimony on behalf of the American Urological Association (AUA) and the American Foundation for Urologic Disease (AFUD).

Mr. Chairman, I would like to thank the committee for their role in establishing the NKUDAB. The Board submitted its report to the Secretary of HHS March 14, 1990, and the information has been distributed to your staff. For the first time the kidney and urology community has a well developed and unanimously adopted long-range plan to combat kidney and urologic disease. AUA and AFUD support fully the recommendations of the National Kidney and Urologic Diseases Advisory Board 1990 long range plan.

The plan offers a blueprint for the future based upon the recognition by the Board of the magnitude of the problem of kidney and urologic diseases in terms of death, morbidity and suffering to the American population. Kidney and urologic diseases number in the hundreds and affect 13 million people nationwide. The financial burden of these diseases is staggering -- approaching $50 billion a year, or more than 8% of the total spent in the U.S. on all disease. There are 7 million hospitalizations and 26 million clinic visits yearly related to these disorders. Moreover, with an aging population we can predict that the prevalence of significant urological diseases, such as urinary incontinence, benign prostatic hypertrophy and prostatic cancer, will actually increase.

In contrast to these dramatic numbers, in FY 1990 NIDDKD committed only about $14 million addressing urologic diseases. Despite the high prevalence of prostatic and bladder carcinoma, for FY 1988 in NCI, only 2.3% ($34 million) of the budget addressed genitourinary malignancies. In summary, kidney and urologic diseases receive only 3% of the NIH budget or only 0.25% of the low estimate of the cost to the country for care of these patients.

It is estimated that at least 10 million adult Americans suffer from urinary incontinence, including 20-30% of community dwelling older people and one half of all nursing home residents. The monetary cost of managing these patients approaches $10 billion a year. More information is forthcoming from a CDC pilot project approved by this committee last year. Moreover, the results of the NIDDKD consensus conference give a blueprint for research initiatives. Other forms of bladder dysfunction, for example interstitial cystitis which afflicts at least 90,000 females and is poorly understood, are also common and yet woefully underfunded. The NIDDKD conference on interstitial cystitis developed strategies to study this problem.

Turning to the aging male, it is of concern that over 350,000 prostatectomies are performed to relieve urinary tract obstruction due to benign prostatic enlargement. The total annual cost exceeds $3 billion. Moreover, there is current controversy concerning the outcome of these procedures and potential long term complications. New exciting experimental advances, including partial purification of prostatic growth factors and the development of drugs to inhibit prostatic growth, offer new strategies for medical management of BPH. However, a confounding factor is the known fact that 10-20% of patients with clinical BPH actually have prostatic cancer. Prostatic cancer is the most prevalent cancer in males, 80% diagnosed in patients over 65, and is disproportionately high in black Americans. Accordingly, we must develop techniques to identify accurately the presence of prostatic carcinoma before medical management of BPH is begun.

It is clear that more funding is mandatory to better understand these diseases, enhance detection, and improve treatment. Fortunately the Appropriations Committee in 1987 established a highly successful vehicle, the George M. O'Brien Kidney and Urological Research Centers, to focus on disease of the kidney and urinary tract. Therefore, we request that Congress appropriate an additional $ 6 million per year to NIDDKD to increase the number of George M. O'Brien Kidney and Urological Research Centers from 6 to 12 with new centers addressing the prevalent diseases of benign prostatic hypertrophy, urinary incontinence and problems in female urology, including interstitial cystitis.

In addition, there are no similar centers in the NCI addressing urologic cancers. Therefore we request that Congress appropriate an additional $10 million per year to the National Cancer Institute to establish six centers to study cancers of the prostate, bladder, kidney, and testis. Furthermore, we recommend that NCI's organ systems program - especially its urologic components - be expanded, supported, and strengthened with increased funding; that an intramural urologic oncology fellowship program be developed; and that the scope of clinical trials for urology be expanded with increased funding.

The critical ingredients for successful research are well trained research investigators. The NIDDKD mandated report on research training needs in urology has been completed as a joint activity of NIDDKD and AFUD and submitted to the Committee. In summary, there is a critically inadequate supply of committed, well trained scientists who can be expected to sustain a long period of independence, creativity and productivity. Thus, in the interval until the recommendations of the NIDDKD/AFUD report are developed, we recommend the addition of training funds to the O'Brien Centers at a level of $300,000 per center.

In addition, we would like to reiterate our apprehension expressed last year concerning the low percent of grants approved by NIDDKD in the area of kidney and urologic diseases. Several major efforts of the Institute are impacting on RO1 funding, including the modification of diet in renal disease study (MDRD), other mandated programs such as AIDS research, and general budgetary constraints. In order to maintain our RO1 base and our general research base in the Institute, we request an additional $12 million dollars to support the KUH for Research Project Grants (RO1) to avoid continued erosion of support for individual investigators.

Finally with a small financial outlay patients with urologic disease would be able to take advantage of the superb scientific expertise at the NIH facilities. Therefore, we request an additional $1 million per year to establish an intramural program in urology at NIDDKD.

Let me also note the important work now underway at the Agency for Health Care Policy and Research. It is responsible for fostering the development of medical care guidelines and research into treatment outcomes and effectiveness. AUA is working closely with the Agency. We urge an $11 million increase in the President's budget request of $49 million for outcomes research.

In summary, AUA and AFUD thank the committee for allowing us to express our concerns. In the past we have found the committee extraordinarily responsive to our needs and we deeply appreciate your actions establishing NKUDAB, the O'Brien Centers, the renal disease and diabetes initiative and the dietary modification study (MDRD,, to mention only a few. We look forward to working with you in a combined effort on behalf of the 13 million Americans suffering from kidney and urologic diseases.

Senator **Adams**. Why does the prostate grow, Doctor?

Dr. **Vaughan**. I would win a Nobel Prize if I could tell you that. Unfortunately, we do not know, however, we have very exciting, new research that suggests that this disease actually starts from people who are age 30 to 35, not when they are 65 or 70, as we previously thought, and there are probably growth factors that stimulate these cells to grow as we get older. If we could have a drug or a device or something that could stop this early growth, or prevent it, then we could avoid the $3 billion a year and 350,000 operations that are done in this country every year.

One other point that I might make is, we are very much in support of the outcome indicator studies that are being planned by Congress to try to get a handle on the best types of treatment for this disease, and the AUA and Dr. Wynburg are jointly preparing proposals to try and study prospectively the different ways of treating prostatic disease.

Senator **Adams**. Thank you very much, Doctor, for your testimony.

STATEMENT OF ROBERT F. MEENAN, NATIONAL ADVISORY BOARD FOR ARTHRITIS AND MUSCULOSKELETAL AND SKIN DISEASES

Senator **Adams**. Our next witness is Dr. Robert F. Meenan, National Advisory Board for Arthritis and Musculoskeletal and Skin Diseases.

Dr. **Meenan**. Thank you, Senator Adams. I have submitted written testimony that I would ask to be entered into the record.

Senator **Adams**. Without objection, your entire statement will appear in the record as though read.

Dr. **Meenan**. Let me take a few moments to summarize. I am a professor of medicine at Boston University School of Medicine, and I am the president-elect of the American College of Rheumatology and a member of the National Advisory Board for Arthritis and Musculoskeletal and Skin Diseases.

I would like to present you with a few comments from my perspective, which includes 10 years as a research center director, funded through NIH, a dozen years as an arthritis clinician and personal experience with a number of family members who have significant arthritis.

My basic message, Senator Adams, is the same as other people have brought before you, and that is that this committee needs to continue its strong support for biomedical research in general. And I urge the committee to consider support of NIAMS and arthritis research, in particular.

Let me make three points to support this argument. The first has been made by other people who have come before you, and that is that the research enterprise is currently woefully underfunded. The Arthritis Institute, for example, has the lowest award rate of any of the Institutes at the NIH, currently around 18 percent. As previously noted, available grants that are already funded are being cut an average of 12 percent. Those are grants of people who are currently doing research and need to absorb significant budget cuts, and the proposed budget for 1991 will be approximately 2 percent increase in real dollars over 1988, when the Institute started.

A second point that I would like to make is the huge economic and personal cost of arthritis. Arthritis and its various diseases is not quite a glamorous set of conditions. People tend not to die from most forms of arthritis, but they suffer from pain and they suffer from a great incidence of disability. It has been estimated that arthritis associated costs account for approximately 20 percent of Medicare hospital charges, and that the overall, direct, and more importantly, the indirect costs of arthritis that come through long-term work disability account for approximately 1 percent of the GNP.

As staggering as those numbers are, they will get substantially worse, because they are estimated to double within the next 30 years, as the population ages. And arthritis is found more commonly in older people.

And finally, I want to point out that this is a critical time for research. A number of people testifying before you have already pointed out, we are facing a great problem with bringing new investigators into these important fields. The article in the New England Journal was already cited, and I think we should all be alarmed that an activity that the United States has such pride in and has been a world leader in we are now starting to lose ground. We simply cannot attract young investigators into a field when their mentors are facing cuts in their budgets and inability of established investigators to maintain funding from the NIH.

We are also at the verge of breakthroughs in many areas, arthritis is among them. Molecular biology has helped us understand genetic susceptibility to certain diseases and may really lead us to major breakthroughs in the near future. And it is a shame to see the engine of the research enterprise being disabled at this propitious time.

PREPARED STATEMENT

So, let me conclude just by making two specific recommendations. In general, I would urge your support of NIH at a level recommended by the ad hoc committee, and second, would support the $50 million increase in the Arthritis Institute budget that has been developed by the interagency coalition, the NIAMS coalition, and also supported by the Arthritis Foundation.

Thank you for your time.

[The statement follows:]

STATEMENT OF ROBERT F. MEENAN

I am Dr. Robert F. Meenan, Professor of Medicine at the Boston University School of Medicine, President-Elect of the American College of Rheumatology, and a member of the National Advisory Board for Arthritis and Musculoskeletal and Skin Diseases. I am honored to have the opportunity to appear before you today to testify in support of the 1991 budget for the Institute.

The National Advisory Board is a public advisory committee charged with providing advice to the Secretary of the Department of Health and Human Services and to the Congress on plans for the enhancement of the programs of the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS). Members of the Board include representatives from various health and scientific disciplines that are concerned with arthritis and musculoskeletal and skin diseases and members of the general public personally affected by these diseases.

Arthritis and other disorders of the musculoskeletal system are the most frequent cause of impairment affecting the adult population. Because a large percentage of those with arthritis are 65 years of age and older, much of the economic burden falls on public resources, such as Medicare. Arthritis and musculoskeletal conditions account for 20 percent of Medicare hospital costs. Children too are affected by arthritis: an estimated 200,000 children have some form of arthritis, and some of them will carry a serious handicap into adulthood.

Musculoskeletal conditions are the second leading cause of activity restriction, and they account for 41 percent of referrals for vocational rehabilitation. Low back pain is the most important cause of activity restriction in young adults and a frequent cause of work disability. The economic cost of arthritis and musculoskeletal diseases is high; direct costs of medical care and associated indirect costs such as those due to lost wages amount to nearly 1 percent of the Gross National Product.

Osteoporosis, a disease in which bone mass decreases, making bone more susceptible to fracture, is an enormous public health problem. It is the leading cause of bone fractures in postmenopausal women and in elderly persons, and it afflicts as many as half of all women in the United States over 45 years of age. The direct and indirect costs of osteoporosis in this country are estimated at $10 billion annually. As a result of the aging of the population, these costs will double by the year 2025 unless action is taken now to implement effective programs for prevention.

As many as 60 million Americans have one or more skin diseases that require a visit to a physician at least once a year. Skin diseases include keratinizing disorders such as psoriasis and the ichthyoses, atopic dermatitis and other chronic inflammatory skin disorders, blistering diseases such as epidermolysis bullosa, and cutaneous manifestations of connective tissue diseases such as scleroderma.

To combat these health problems, the NIAMS supports basic and clinical research, research training, and professional and patient education. Although steady progress has been made toward better understanding these diseases, funding has not increased to any appreciable degree since the Institute was established. In real terms, the 1991 budget request represents a 2 percent increase over 1987, the year the NIAMS became operational. Funding for research project grants has increased slightly, and funding for research centers and other research and training programs has decreased. As a result, opportunities for significant advancement in arthritis and musculoskeletal and skin diseases have passed unfulfilled.

Almost two-thirds of the NIAMS budget is spent on research project grants. Under the budget request for 1991, the Institute will be able to support 150 new projects, far fewer than the 179 funded in 1987. Since its inauguration as a separate Institute, the NIAMS has consistently had the poorest payline of all the Institutes at the NIH. Under the budget request, the Institute will make awards only to those investigators who score in the top 15 percent of all applicants. Reductions from approved budgets will continue at 12 percent. This is a strong disincentive to individuals interested in applying their knowledge to the challenges presented by arthritis and musculoskeletal and skin diseases. The Board strongly recommends a payline corresponding to a percentile rank of 30 to 35, with no reductions from budget levels recommended by the peer review groups.

The Board is convinced of the importance of centers for both basic and clinical research. Centers have a multiplier effect on research collaboration, faculty development and recruitment, postdoctoral research training, and graduate medical education. The Board recommends that centers be funded at full recommended levels. If research on skin diseases is to benefit from the value of centers, it is vitally important that the full complement of six skin core centers be funded, as recommended by the academic dermatology community. Productive new specialized centers could also be established in such areas as pediatric rheumatology, lupus, scleroderma, and low back pain.

Of particular concern to the Advisory Board is the lack of progress in replenishing the ranks of researchers. Data indicate a strong relationship between the length of postdoctoral research training and subsequent success in applying for independent research support. The Board recommends an expansion of both research training and the critical mechanism of research career awards, the midlevel bridge between postgraduate education and investigative medicine. Manpower development must be continued at the same level as current research, or the ability to undertake future initiatives will be crippled.

Research and development contracts provided the mechanism for the conduct of clinical trials to evaluate the efficacy and safety of new therapies. The Board recognizes thjs critical need and recommends that enough funds be provided to bring the contracts mechanism up to the NIH average of 7 to 8 percent of the total Institute budget.

The NIAMS Intramural Research Program should be expanded and enhanced. In particular, the establishment of a Laboratory of Connective Tissue Biology within the Intramural Program is highly recommended. This program will complement the newly created intramural efforts in pediatric rheumatology research, orthopaedics, and skin biology. Ongoing construction and renovation on the NIH campus have made available sufficient new space for expansion of the laboratory programs. The Board strongly recommends that NIAMS be provided with additional funds and positions to support this expansion adequately in terms of personnel and equipment.

The dissemination of scientifically accurate information in language appropriately targeted to health care professionals, the general public, and patients and their families is critical if research findings are to result in practical applications to treat, cure, and alleviate the suffering these diseases bring to millions of Americans. In March 1989, the Board planned and sponsored a conference on Financing Patient Education in Arthritis and Musculoskeletal and Skin Diseases. A central issue that emerged from the conference is the need to develop standards for educational programs in arthritis and musculoskeletal diseases. Followup activities of the conference are aimed at developing standards for patient education in arthritis and musculoskeletal diseases.

Much has been accomplished in addressing the problems of arthritis and musculoskeletal and skin diseases, but clearly there is a great deal yet to be accomplished and much work to be done. In response to this challenge, the research community must pursue new horizons in basic and clinical research. For this to be done, it is imperative that the Congress appropriate funds sufficient to permit the Institute to keep pace with these opportunities and to undertake new initiatives so vital to research in arthritis and musculoskeletal and skin diseases.

Senator Adams. Thank you, Doctor. The message is coming through loud and clear and very well done on the results of the recommendation of the ad hoc committee for NIH, generally.

I want to focus on arthritis for a minute with you, because I agree with you that it will become, unless solved or alleviated, an increasingly expensive, as well as all the other horrible things combined with it, as our population grows older.

Tell me a little bit about arthritis and where you are with the research. You just mentioned that there was some feeling that biomedical research might cause an improvement, because as far as I know, people just suffer with it, and various things have been rubbed on it, heated, chilled, everything else. Could you give me a little enlightenment?

Dr. Meenan. There are two prototypical diseases. One is osteoarthritis, which is thought to be a more wear and tear disease of older Americans, and researchers recognize that there are changes in cartilage and changes in bone that predate the development of symptoms, and it may lead to—if we understand better what those processes are, we may be able to intervene.

The other disease is rheumatoid arthritis, which is, in most cases, a much more serious form of arthritis. It is inflammatory, it affects multiple joints, and in molecular biology, research has shown us that there are——

Senator Adams. That starts at younger ages?

Dr. Meenan. It can start at any age. There are children with juvenile rheumatoid arthritis. It goes through the entire spectrum of aging. The risk of any individual getting rheumatoid arthritis actually does tend to increase somewhat with age, up into the fifties and sixties even. And we are now recognizing new sequences in the gene that may confer susceptibility to this condition, because they resemble sequences in viruses, and that may lead to a great deal of insight into how this process starts and, eventually, to how we can treat it.

Senator ADAMS. Well, it just has always struck me because I know, really, few people that are elderly that are not afflicted in some way by some type of arthritis, and they obtained this along the way, so it is a general condition, and yet we seem to know very little about it, and people, as you say, at that age, most of them do not die from it, but they certainly suffer.

Dr. MEENAN. Well, the striking thing is, I think, for a variety of reasons now, we are dispensing with the old notion that arthritis is part of aging, and if you are going to live to be 60 or 70, you just have to accept it. We recognize that as people age now, they expect to remain active and they do not want to be disabled from arthritis, and we are also recognizing that there are many people in their seventies and eighties who do not have arthritis, certainly not to the level that disables them. And we really need to understand why people get it, and why there is a number of people who do not.

Senator ADAMS. Thank you very much, Doctor. I appreciate your testimony.

STATEMENT OF JOE D. COULTER, UNIVERSITY OF IOWA COLLEGE OF MEDICINE, ON BEHALF OF THE ASSOCIATION OF AMERICAN MEDICAL COLLEGES

Senator ADAMS. Our next witness is Dr. Joe D. Coulter, University of Iowa College of Medicine, Association of American Medical Colleges. Senator Harkin welcomes you here from your connection with Iowa. I once lived in Iowa City, which was not too far away, so I welcome you also. So, Doctor, we look forward to your testimony.

Dr. COULTER. My name is Joe Coulter and I am testifying on behalf of the Association of American Medical Colleges, which commends you and your subcommittee for continued support of medical education and the research programs under your jurisdiction.

The association's members believe that the administration's fiscal year 1991 budget request for the National Institutes of Health for the research and the research training programs of the Alcohol, Drug Abuse, and Mental Health Administration, are truly inadequate to meet the scientific opportunities that are currently available. The association has submitted a statement for the record detailing our concerns.

Senator ADAMS. Without objection, your entire statement will be included in the record at this point.

Dr. COULTER. Thank you, sir. Let me just say that the association's members believe that it is a cruel irony that at a time of almost unlimited scientific potential to address diseases and the disabilities that afflict millions of Americans, that many potentially promising research projects are going unfunded, and that many of the research projects which are funded are supported at levels that are so low or have been cut back, as you have heard, that the scientific progress that is being made is being significantly reduced.

This lack of funding is not only slowing the scientific progress, because specific research ideas are unsupported, a more serious consequence and one that threatens the future of the Nation's medical research effort, is that the scientists are becoming discouraged and are turning away from research. At the same time, many of our best and brightest young people are no longer considering careers in medical research.

The association fully supports the recommendations of the ad hoc group for medical research funding for $9.2 billion for the NIH and $1.2 billion for ADAMHA, the Alcohol, Drug Abuse, and Mental Health Administration programs. This proposal addresses the critical shortfalls that the administration's request lacks by restoring full funding for research project grants and for centers, and by providing a measure for growth in supporting opportunities for new people and new ideas.

A specific NIH program that I would like to call your attention to, however, is the Biomedical Research Support Grant Program, which provides funds that may be used at the discretion of the grantee institutions to support pilot projects, recruit new scientific talent, and develop and maintain shared resources. The administration's proposal to reduce the BRSG funding to $11.8 million in fiscal year 1990 and 1991, would essentially destroy this program. It used to be, and it is this year, at $55 million. This would deny our medical centers and other research institutions an important source of support for our young scientists for emerging ideas and to pick up some of the shortfalls that we have been seeing in research grant funding.

With regard to health manpower, the association is pleased with the proposal to increase funding for the National Health Services Corps, the Exceptional Financial Need Scholarship Program, the Excellence in Minority Research Centers Program, and the Disadvantaged Assistance Program. The association believes that funding should be continued for programs under title VII of the Public Health Service Act for training and primary care, preventive medicine, geriatrics, and to address the geographic maldistribution of physicians in our society.

PREPARED STATEMENT

Congress should also turn away from the administration proposal to phase out the Health Education Assistance Loan Program. We need this.

Again, we thank you for support of the programs in the past, and look forward to working with members of this subcommittee and the staff in this endeavor.

[The statement follows:]

STATEMENT OF JOE D. COULTER

The Association of American Medical Colleges (AAMC), which represents all 127 accredited U.S. medical schools and their students, 420 major teaching hospitals and 92 professional and academic societies, appreciates this opportunity to comment on the FY 1991 appropriations for the Department of Health and Human Services. The Association's members, who play a major role in implementing the federal government's programs for medical research and health professions training, recognize and commend the continued support that this Subcommittee has provided to the research and education programs under its purview.

Medical Research: The investment that Congress has made in medical research has enabled the United States to develop a comprehensive system to explore and understand the nature of the diseases and disabilities that affect millions of Americans. However, there is a growing concern within the academic medical community that the federal commitment to medical research and research training has not kept pace with either the challenges posed by the diseases and disabilities that afflict millions of Americans or the opportunities available to combat these conditions. Unfortunately, the Administration's FY 1991 budget request does little to allay this concern.

The Administration's FY 1991 requests for the National Institutes of Health (NIH) and for the research and research training programs at the Alcohol, Drug Abuse and Mental Health Administration (ADAMHA) do not provide sufficient funds to meet the scientific opportunities currently available. For the NIH, the Administration's budget would not even fully support the current level of effort, falling more than $460 million short of the NIH's current services estimate of $8.4 billion. The Administration's proposed 4.7 percent increase is below the NIH's projection of 5.9 percent for the Biomedical Research and Development Price Index in FY 1991.

In an effort to increase the number of NIH competing research projects to the proposed 5,095 awards, the Administration would need to continue the recent pernicious practice of reducing the size of research project grant awards (both competing and non-competing) by significant amounts below the levels recommended by study sections. In FY 1991, these so-called "downward negotiations" would amount to an average cut of 10 percent for noncompeting research project grants and 14 percent for competing awards. These figures are averages for the whole of NIH; cuts for some individual institutes are higher. These reductions are an attempt to maintain a semblance of stability in the number of competing research project grants awarded each year. However, cuts of this magnitude are a false economy; they simply result in less research. In addition, these cuts impede sound financial planning and management by institutions and individual scientists. Further, they erode the key role of the peer review process whose grant awards are based on scientific merit. In effect, this practice of reduced levels of funding disregards the peer review-based relationship between assessment of scientific merit and level of funding necessary to pursue the research project.

These so-called downward negotiations are not limited to research project grants. Research centers also have been reduced, some by as much as 30 percent below recommended levels. The Administration's FY 1991 request would continue these reductions. If these cuts were restored, as they should be to both research project grants and research centers, the Administration's request would need to be nearly $8.6 billion.

The Ad Hoc Group for Medical Research Funding -- a coalition of approximately 140 scientific and professional societies, research institutions and voluntary health agencies -- proposes $9.237 billion for the NIH. The AAMC endorses this proposal, which is $1.6 billion over FY 1990 and $1.3 billion over the Administration's request. The Ad Hoc Group's proposal addresses the critical shortfalls in the Administration's request by restoring full funding for research project grants and centers and providing for a measure of growth to continue to provide opportunities for new people and new ideas. To achieve these objectives, the Group proposal would provide sufficient money to fully fund approximately 30 percent of competing research project grant applications anticipated in FY 1991.

The Ad Hoc Group's proposal also recognizes the need for additional funding to support the increased commitment base that has resulted from extending the average length of research project grants. Over 50 percent of the research project grants awarded in FYs 1988-90 were for 5 years or more, compared to approximately 20 percent in the mid 1980s. These longer awards enable scientists to devote more time to the conduct of research rather than spending time preparing more frequent applications. Lengthening the award period, however, increases the amount of funding needed to support noncompeting research project grants because it keeps more grants in the system for a longer period of time.

The Ad Hoc Group's proposal also would fully fund existing research centers and support a very few additional centers, restore the Biomedical Research Support Grant program to its FY 1989 level of $56 million (in addition to maintaining the Administration's proposal for $6 million to support the Minority High School Summer Research Apprentice Program), support 12,020 National Research Service Award trainees (as proposed by the Administration) and provide additional funding to support full tuition, support approximately 250 additional research career awards, bringing the total to nearly 1,800, provide approximately $150 million to support the first year costs of major new clinical trials that are ready to begin but are currently unfunded, and fund the Administration's request of $88.6 million for renovation of facilities on the NIH campus.

As with its proposal for the NIH, the Administration's FY 1991 request of $932 million for research and research training at ADAMHA is insufficient to meet the cost of maintaining current services. The number of competing research project grants proposed for FY 1991 is 604 -- a decrease of 268 from FY 1990. As a result, the Administration's request would fund only 20 percent of approved applications, down from 33 percent in FY 1990. In addition, this number of grants would be supported at the cost of an average reduction of 8 percent from study-section recommended levels.

The Association supports the Ad Hoc Group's FY 1991 proposal of $1.197 billion for ADAMHA research and research training, which recognizes the need for adequate funding to expand all areas of ADAMHA's research and research training mission. Particular emphasis is placed on the following areas:

- According to the Institute of Medicine, as many as 7.5 million children and adolescents experience serious mental and emotional disorders. The Ad Hoc Group proposes $60 million over the FY 1990 level to initiate a National Plan for Child and Adolescent Disorders;

- The National Plan for Research on Schizophrenia and the Brain requires a sustained commitment of resources to develop more effective treatments for schizophrenia and to accelerate the pace of research advances in the neuroscience of mental illness, including manic-depressive mental illness consistent with the "Decade of the Brain" initiative. The Ad Hoc Group proposes $150 million above the Administration's budget for this effort.

The Ad Hoc Group proposal also would provide increased support for research on the neurological and genetic aspects of addictive disorders, the relationship between drug abuse and HIV infection and mental disorders in the elderly. This proposal would nearly double the Administration's FY 1991 request for competing research project grants, allowing ADAMHA to fund 40 percent of approved applications. The number of research centers would be increased slightly. The Ad Hoc Group proposes an increase in research training from 1,453 trainees in FY 1990 to 2,670 in FY 1991. It is essential that a significantly increased investment in research training be made in the areas of mental health and the addictive disorders. Particular emphasis is placed on the support of new clinical investigators.

Health Manpower: The AAMC is pleased with the Administration's FY 1991 budget proposal to increase funding for the National Health Service Corps, for a scholarship program for exceptionally needy health professions students, and for programs to address minority underrepresentation in the health professions. Funding for minority recruitment and retention programs and the Excellence in Minority Health program helps medical schools in their efforts to attract and train more minority students. The persistent problem of minority underrepresentation in the health professions should continue to be a focus of federal health manpower efforts.

The geographic and specialty maldistribution of physicians in the U.S. also remains a critical problem. The Administration's request of $64 million to support the loan repayment and scholarship programs in the National Health Service Corps should begin to alleviate the serious shortage of providers in the 1,900 communities in this country still designated as health manpower shortage areas. The availability of additional scholarship and loan repayment funding also will help disadvantaged medical students and highly indebted residents interested in practicing in underserved areas.

The AAMC is very disappointed that the Administration's budget proposal again seeks to eliminate a number of health professions training programs in Title VII of the Public Health Service Act that are also important in addressing physician maldistribution. In 1988, the Congressionally-mandated Council on Graduate Medical Education (CoGME) recommended the expansion of federal funding of training programs in primary care, preventive medicine, geriatrics and of programs that seek to correct geographic maldistribution. These programs have been effective in addressing specialty and geographic maldistribution problems, and they should be continued.

Congress should also reject the Administration's proposal to phase out the Health Education Assistance Loan program, which would have adverse consequences for approximately 30,000 health professions students who need the program to help finance their education. The Administration's rationale for phasing out the program apparently rests on the availability of other financial aid programs. We contend that even with increases in the NHSC loan repayment and scholarship program, the HEAL program will be needed by medical and other health professions students. In addition, we oppose the proposed transfer to the HEAL insurance fund of $15 million from the Health Professions Student Loan (HPSL) and Nursing Student Loan (NSL) programs. Such a transfer would siphon resources away from a program that helps disadvantaged students. Moreover, since the Administration expects the insurance fund to have an ending positive balance in 1991 of $23.3 million, the need for the transfer is questionable.

The Association regrets that time constraints limit the opportunity to discuss other important health programs under the Subcommittee's jurisdiction. We appreciate the diligence with which the Subcommittee approaches its responsibility, and look forward to working with members and staff to achieve our mutual objectives.

NATIONAL HEALTH SERVICE CORPS

Senator Adams. Doctor, I have two questions. First, do you think the $64 million, which has been allocated for the National Health Service Corps will be sufficient to support the loan repayment and the scholarship program for the National Health Service Corps?

Dr. Coulter. That is an improvement. I think what has happened here is there has been some reshuffling of resources from the BRSG programs over into some of these others. We do endorse the increase that we are seeing in the National Health Service Corps in those aspects of the administration's proposal. It is the concern over the loss of this biomedical research support grant funding that we have some of our greatest concerns and want to see a recovery there.

Senator Adams. Dr. Coulter, in many ways, I have been waiting for you, maybe someone else is the appropriate spokesman for this, but can you give me a statement as to why it is at this moment in time when we have this enormous change in our ability to do biomedical research, both through the digital computer, the whole DNA chain analysis, and all of these various things, that there should not be an increase in medical research based upon this? Why have you been told or what is your understanding, because I gather from these various witnesses that this downward negotiation process has not been a negotiation; it has just been downward. [Laughter.]

And I would just like to know whatever it is that you would like to say about that. Why is it happening? I mean, I understand budget restrictions. I was your first budget chairman in the House of Representatives, and I played those games for years. But this just seems to me to be—well it is the year 1990 and it is an exciting year in this particular field, why we should be reducing it.

Dr. Coulter. There are several factors that have to be taken into consideration here. Indeed, your perception is the same perception as the scientists and the health voluntary groups and society generally has, that somehow the support for the NIH and ADAMHA and biomedical research has been cut. Well, it has not been cut. This committee has been very generous in providing small increases over the years.

What has happened, I think, are two things. One is that in the administration of the grants program at NIH, we have taken a good step forward in trying to extend funding for the very best investigators. Rather than having each grant come up every 3 years, we have taken the best scientists and said, we will fund you out to 5 years or 7 years, so that you do not have to go through this grants writing game so much. The scientific community supports that. That is a good idea. But, obviously, it mortgages you in the out years.

That is a mechanical aspect, which has then led to the necessity of the institutes simply saying we do not have the money to fund this new proposal, this new opportunity or this young investigator who is starting out.

So, we have made a good investment. I think we have used wisely the increased resources that this committee has brought to the scientific community. But I think you pointed a finger at the kinds of things that, as a scientist, I see as the tremendous opportunity, particularly in cell and molecular biology. I feel we are living in the most exciting time. Rather than sometimes being optimistic and promising something when we come to you and ask for funding, I think we are really on the verge of being able to get at things, the genetic basis of many of these diseases, the whole issue of gene regulation, and the opportunity that human genome project has for us. I think these are tremendous.

And it is just especially frustrating as a scientist to feel that we are on the verge of this, to see the young people turning away, the opportunities being lost, and it should not happen.

Senator **ADAMS**. Well, that is what is concerning me, and that is why I asked you the question. This is strictly my opinion, and it does not represent that of the committee, but just from having dealt in the health field and having been in Congress since 1964 and in administrations and a whole lot of places—I am what you might call an old dog at this—that there has been sort of an administration feeling of tiredness toward NIH, generally. Well, it has been there a number of years and it has always there and that happens with older agencies sometimes.

I put this out because you will communicate to a number of people and there are a number of others in this room who can also. There needs to be an infusion of the fact that there is something very new happening in the world, and that this is not the same thing that has been going on.

It is the same problem that the space programs suffers from. It is very exciting at first and everybody knows about it, and then pretty soon, nobody pays any attention to it unless they have something new. I just happen to feel, from the institutes that are in my area, the private companies that are in the new technology corridor and so on, that are doing—and they are very small. I mean, each one fits in a little room and there is three or four people in there, and that our universities and our hospitals there are really not receiving the amount that they should for dealing with these people to get a transfer back and forth so that the United States takes advantage of this incredible new opportunity.

Because I agree with you. I think that in genetics and in all the work that has been done in DNA and our ability to more quickly process information throughout computerized systems, we have an opportunity. So, that was why I asked you the question, and I appreciate your answer.

Dr. **COULTER**. Thank you for the opportunity.

Senator **ADAMS**. Thank you, Doctor, very much.

STATEMENT OF EMIL PAGANINI, PRESIDENT, RENAL PHYSICIANS ASSOCIATION

Senator **ADAMS**. Our next witness is Dr. Emil Paganini, president of the Renal Physicians Association.

Dr. Paganini.

Dr. **PAGANINI**. Thank you, Senator Adams, for the opportunity to have this time. We have submitted written testimony. We would like that submitted to the record, if at all possible.

Senator **ADAMS**. Without objection, it will be included in the record in full as though given.

Dr. PAGANINI. The society which scorns excellence in plumbing as a humble job and tolerates shoddiness in philosophy because it is considered an exalted profession, will have neither good plumbing nor good philosophy, or to put it in another way, neither its pipes nor its theories will hold water. [Laughter.]

Senator ADAMS. And if anything goes wrong, it is a disaster.

Dr. PAGANINI. I am chairman of the section of dialysis and extracorporeal therapy at the Cleveland Clinic Foundation, a member of the department of artificial organs, newly elected president of the Renal Physicians Association. But the thing that I am most proud of is that I am a physician, an M.D. after my name. I am a practicing physician.

And I would like to come here and tell you that we at the Renal Physicians Association are very happy that the newly organized and developed Agency for Health Care Policy and Research has been developed. We would like to thank you, the Congress, for having developed this in a joint effort with medicine for evaluating the effectiveness of health care dollars spent.

I would like to bring two points up, however. The first is the adequate funding of this newly developed agency. It is funded, currently, as $110 million overall, $34 million coming from inside, and other sources making up the difference. I would like to point out that we are, as you have heard before in the renal area, spending $50 billion for renal-related disease support, and in the specific area of dialysis, $4 billion this year in support of end-stage renal disease.

So $110 million to look at effectiveness of all diseases, less than one-hundredth of 1 cent on the capital dollar, where 13 cents out of every budget dollar is going for health care, seems a little bit low. I would just please ask that you do fund this, not out of NIH funding to lower their funding, but to give more to effectiveness research. I would also like to say that we would appreciate physician involvement at all levels, not only the research physician but also the front-line practicing physician.

PREPARED STATEMENT

A nice example of this is the USRDS, the U.S. renal data system, in which there is cooperation among agencies, the NIH picking up a lot of the research arms and HCFA, a traditional area of just health care financing has also gone through helping and financing the areas of expenditure for health care. We believe, therefore, that adequate funding, now and later, in this new agency is important, that the involvement of practicing physicians is an extremely important portion of that, so that not only the efforts can be effective but also meaningful and so that both our philosophy and our plumbing will hold water.

Thank you.

[The statement follows:]

STATEMENT OF EMIL PAGANINI

The Renal Physicians Association, (RPA), is a professional organization of nephrologists whose goals are to insure optimal care under the highest standards of medical practice for patients with renal disease and related disorders, to act as a national representative for physicians engaged in the study and management of patients with renal disease and related disorders, and to serve as a major resource for the development of national health policy concerning renal disease. We are pleased to have the opportunity to provide the subcommittee with our testimony concerning fiscal year 1991 funding for the newly established Agency for Health Care Policy and Research, (AHCPR).

The Agency was established under the Omnibus Budget Reconciliation Act of 1989 (Public Law 101-239), to "enhance the quality, appropriateness, and effectiveness of health care services, and access to such services, through the establishment of a broad base of scientific research and through the promotion of improvements in clinical practice and in the organization, financing, and delivery of health care services".

Beginning prior to the establishment of the Agency, (when such activities were conducted through its predecessor organization, (the National Center for Health Services Research), the RPA has assumed a strong stance in support of increased attention to, and funding for, health science research. Health Science research (or "medical care research") represents research on the organization and delivery of medical care, including clinical practice. Specific types of activities include clinical decision-making, (including research on development of clinical strategies and clinical reasoning), health services research, (for example studies in clinical epidemiology, research relating to ethics of practice), and medical education research.

With the creation of the new Agency, RPA sees positive steps being taken to expand the prior level of federal commitment to health services research (as of FY 90, there were only about 2000 professionals working in health services research, and only 40 university-based centers or institutes). We see as critical the continuation of this trend to increase emphasis on health services research. The Administration-proposed budget for the AHCPR for FY 91 is just over $110 million in total obligations, an 11.5 percent increase over current fiscal year obligations. Of this amount, the appropriation from general funds of the treasury is just over $39 million, with the remainder of the amount coming from the medicare trust funds, and funds transferred from elsewhere within the Public Health Service.

The Physician Payment Review Commission (PPRC) has recommended that several hundred million dollars per year be provided for clinical effectiveness research and technology assessment; and that tens of million of dollars should support the development, dissemination, evaluation of practice guidelines, and medical review criteria. The Administration's budget proposal for AHPC&R obviously falls short of this recommendation, but does represent a step in the right direction.

The costs associated with treatment of renal disease alone are staggering: Medicare expenditures for 160,000 end stage renal disease patients in 1987 were $3.4 billion, and as our population expands (including a projected increase in those aged 65 and older and in minority groups) we can expect annual costs to escalate further. Recognition of this situation has brought us to the realization that health services/outcomes assessment studies are indisputably necessary if we are to come to appropriate conclusions about optimal care and achieve necessary health care cost containment.

$49 million of the budget request for AHCP&R is for the medical treatment effectiveness program, representing a 29 percent increase over the current fiscal year level. Two-thirds of the amount comes from the medicare trust funds, as stipulated under the Social Security Act. The portion of the request appropriated from general funds of the treasury (one-third of the request) is about $14 million.

The medical treatment effectiveness program supports the development of scientific knowledge about patient outcomes through the following activities:

- developing of methodologies to support outcomes research,
- developing and augmenting databases on outcomes
- supporting and conducting outcomes research
- disseminating information derived through such research

- providing periodic review and updating of clinically relevant guidelines, standards performance measures and review criteria.

The RPA strongly supports this program which will provide information to both patients and practitioners which is needed as we work to improve health care delivery and to optimize utilization of scarce resources. RPA would like to see additional monies from the general fund appropriated to the Agency for medical effectiveness programs, based on the importance of such programs to our efforts at the national level to improve the quality and appropriateness of health care services, and access to care. Variations in services and resources have been demonstrated for many medical conditions. Adequate funding is essential so that the relationships between such variations and patient outcomes can be examined. In addition, we believe that additional funding should be directed toward developing more sophisticated methods for assessing health care outcomes and for improving clinical decision-making.

Under its authorizing legislation, the Agency's Administrator must ensure development of practice guidelines for at least three clinical treatments or conditions accounting for a large portion of medicare expenditures and having significant variations in frequency or type of treatment provided. RPA supports the research activities of the AHCP&R and the development of practice guidelines by panels convened under the Agency's Forum for Quality and Effectiveness in Health Care. We believe that the input of practicing physicians is an an essential part of guideline development efforts. We urge the Agency to actively pursue substantial physician involvement in all aspects of effectiveness research and guideline development.

The RPA has been participating with other national medical specialty societies in the AMA's practice parameters forum, and has endorsed a compilation of requirements for the development of practice guidelines. The resulting format includes the following attributes:

- development by/or in conjunction with, physician organizations

- incorporation of methodologies integrating relevant research findings and appropriate clinical expertise

- constitution so as to be as comprehensive and as specific as possible, and based on current information

- necessity of wide dissemination

The RPA is now pursuing the development of practice guidelines relating to kidney disease. Given the costs associated with the provision of health care to the populations of individuals with kidney diseases, and the vulnerability of the government's ESRD program, we believe that funding of such studies should be seen as a high priority by the Agency. We believe that the appropriations committees should take the initiative to provide increased funding for the AHCP&R's medical effectiveness program directed to support of studies relating to kidney disease outcomes assessment and clinical care decisions.

$51 million of the Administration's request for the Agency is for the Agency's general health services research and health care technology assessment programs. Approximately $34 million of this amount is included for evaluations in general health services and technology assessment. Close to two-thirds of that amount goes to research on the delivery of services to minorities and the disadvantaged, rural health research, primary care, health promotion and disease prevention activities, and medical liability. In the renal area, there are several important issues which merit analysis under such a program of evaluative research. (Insert relating to renal disease specifically)

General research and dissemination of information on health care services and on systems of delivery of such services will be supported at essentially the FY 90 level under the Administration's budget. The RPA believes that the increasing importance and national trend in support of activities in this area dictates that new budget authority be increased for FY 91 for programs in such areas as health care services in rural areas, clinical practice, health care technologies, health care costs, and long term care.

The RPA has had a long-standing commitment to health services/medical effectiveness research, particularly as it impacts the delivery of care and services to people with kidney diseases. We appreciate the opportunity to contribute to the appropriations committee's deliberations concerning FY 91 federal funding for this important area of research.

Senator **Adams**. Thank you very much. I see in your testimony you have several figures regarding funding, so let me just ask you this question. You may have answered it by a combination of figures, but I do not have it clearly in mind.

RPA recommends the Appropriations Committee take the initiative and provide increased funds to the Agency for Health Care Policy and Research. What amount of additional funding does RPA recommend in order to fund that agency for its medical effectiveness program?

Dr. **Paganini**. We have looked at PPRC and their recommendation of several hundred million dollars for funding effectiveness research, and we have also looked at their recommendations for funding research in practice guidelines, so that physicians can get their act together, if you will, and practice in a sense that is more efficient, more cost effective. We are talking there, tens of millions of dollars, so we are actually saying that you could easily double the allocation and have adequate top draw issues being looked at. So I would say, beyond that, absolute numbers I could not give you, but I would say at least a double of what was allocated.

Senator **Adams**. Thank you very much for your testimony.

STATEMENT OF LAWRENCE RIGGS, MAYO CLINIC, ON BEHALF OF THE NATIONAL OSTEOPOROSIS FOUNDATION

Senator **Adams**. Our next witness is Dr. Lawrence Riggs, Mayo Clinic, National Osteoporosis Foundation.

Dr. **Riggs**. Thank you, Senator Adams, and good morning. I appreciate the opportunity to summarize this statement and I also would like to have the full statement put into the record.

Senator **Adams**. Without objection, your full statement will appear in the record as though read.

Dr. **Riggs**. And thank you for your patience, it's been a long morning for you, I know. I am a professor of medicine, a clinician at the Mayo Clinic and also a clinical investigator in osteoporosis research. I am here on behalf of the National Osteoporosis Foundation of which I am a vice president. This is a voluntary nonprofit organization representing thousands of concerned citizens, as well as professionals, with the goal of the prevention and treatment of osteoporosis.

Osteoporosis really is an enormous public health problem. It affects one-half of the population of postmenopausal women, and one-quarter of the population of aging men with fractures, that is a total of 24 million Americans.

We urge the Congress to increase the funding for osteoporosis research to $50 to $60 million per year, to increase the funds available to the NIH for research in this area. It is very important that the NIH maintain its leadership role in research related to osteoporosis. In fact, as you have heard from many others, it is certainly true in this case for osteoporosis, we are right at the point where very much can be accomplished.

Right at this time, however, we have the same problems as others have mentioned. In the funding for osteoporosis research, only 15 to 20 percent of the approved project grants will be funded this year. Now, the total funding for osteoporosis research represents only a small fraction of the total cost, only about 0.2 percent.

So, obviously, if we are going to make progress, that needs to be increased.

I see patients in my practice every week with osteoporosis, and I am always sad, because this is a condition that is essentially preventable. Many of these patients will become institutionalized, require community-based care. Just for example, a patient of mine, a widow, 78 years old, was able to live at home, drive a car, and do her own shopping. She broke her hip from a fall in the kitchen, and she now is in a nursing home at $25,000 a year, probably the rest of her life.

With a reasonable infusion of research dollars, however, we have the potential to eliminate this disease within the next 20 to 30 years. Now, it is really important that we move now, because, high as the figures are, there is a coming epidemic of osteoporosis. That is because of the aging of the population. The elderly are the fastest-growing segment.

Even correcting for age, there is an absolute incidence increase in osteoporosis, probably from diet and other abnormal behavioral factors that can be eliminated. And we are reaching the point where we can begin to manipulate bone turnover, the mechanisms by which bone is built and is absorbed and understanding these and manipulating them pharmacologically.

PREPARED STATEMENT

For the next 20 to 30 years, if nothing is done, the cost will then be $30 to $60 billion a year. The time to prevent this epidemic is now.

Thank you very much, Mr. Chairman. I would be happy to answer any questions you have.

[The statement follows:]

STATEMENT OF B. LAWRENCE RIGGS

Mr. Chairman, I want to thank you for the opportunity to provide testimony on the issue of increased funding for research on osteoporosis and related metabolic bone disorders. On behalf of the thousands of members of the National Osteoporosis Foundation (NOF) and the many scientists, health professionals and consumers concerned about osteoporosis, **we urge you to markedly enhance the amount of funding for osteoporosis research to between $50 and $60 million.** Funds should be allocated to the National Institute on Arthritis and Musculoskeletal and Skin Diseases, the National Institute on Aging, and the National Institute of Diabetes, Digestive, and Kidney Disorders as the principal institutes conducting research on osteoporosis and other metabolic bone disorders.

Osteoporosis is one of the nation's most significant health problems, affecting between 25 and 30 million people, mostly older men and women. This condition is characterized by the excessive loss of bone tissue which leads to fractures most typically of the hip, wrist, and spine. Osteoporosis, known as the "silent thief," is the end result of a generally painless, gradual loss of bone tissue accompanying aging.

Osteoporosis leads to 1.3 million bone fractures a year, or about 70 percent of all fractures in people over age 45 and over 90 percent of all hip fractures in adults. Each year, about 250,000 hip fractures, 500,000 fractures of the vertebrae, 200,000 fractures of the wrist, and another 200,000 fractures at other limb sites are attributed to osteoporosis.

Hip fractures are the most debilitating outcome, resulting in lost independence, suffering, increased mortality, and substantial financial expense. Approximately 15 percent of elderly hip fracture patients will die within one year of sustaining the fracture and over 50 percent of the survivors will be permanently disabled, no longer able to live independently.

For many, hip fractures will lead to permanent institutionalization in a long-term care facility, causing a significant impact on this Nation's costs for long-term care. The costs of acute and long-term care for hip fractures, alone, is well in excess of $7 billion annually.

The yearly cost of osteoporosis in the United States is estimated to be $10 billion, a figure that has grown rapidly and is expected to reach between $31 and $62 billion in just 30 years. The potential is great that osteoporosis will attain epidemic proportions as the older population increases in number if sufficient efforts are not made now to thwart this mounting public health problem.

One can readily imagine the destructive impact of osteoporosis in the future if the development of this condition remains unchecked. The effect on the financial viability of the Medicare system alone could have far reaching consequences.

We believe that a concerted attack on osteoporosis is overdue and cannot wait until the next generations of women and men develop this devastating condition. We must allocate sufficient funds in order to assure a full complement of investigator-initiated research on osteoporosis.

Adequate funding is crucial if researchers are to be attracted to the National Institutes of Health (NIH) where they will continue seminal work in basic biomedical research -- work that is essential to unlocking the secrets of bone biology. The general underfunding of biomedical research has led to a slow relinquishing of the role of NIH as the world leader in biomedical research, thus allowing the private sector to frame the research questions. While the private-public sector relationship is important, it must be a partnership of equals with NIH providing the opportunity for unlimited discovery.

It has been estimated that for every $1 invested in medical research, there is a $13 return on the investment as a result of improvements in absenteeism, increased productivity, and diminished health care costs. Both in economic and human terms, research into osteoporosis is cost effective; yet, today we spend only about $1.00 per affected person on research. Even in times of tight budget constraints, such as those we are experiencing today, the short-term cost of research as compared to the long-term gain must not be overlooked.

Some of my colleagues believe that we are close to achieving important breakthroughs in our ability to understand osteoporosis. Only in the last two years we have found estrogen receptors in bones, thus providing a tantalizing clue to the use of estrogen in protecting against bone loss and giving us a window on potential treatments. Also, estrogen antagonists that are used for treatment of estrogen-dependent tumors (breast and uterus), were found to have estrogen-like effects on bone. Thus, other antiestrogens may be developed that prevent bone loss but lack some of the side effects of estrogen.

In addition, we have discovered bone growth promotion molecules within bone tissue, molecules that can be harvested for use in treating osteoporosis.

Discoveries of these types are critical but they require a commitment to funding research that can only be made at the federal level.

We believe that osteoporosis is essentially preventable but that further research is needed to determine the extent to which lifestyle decisions can affect the development of this condition. With that information, it will be possible to greatly reduce the prevalence of this condition in future generations.

The National Osteoporosis Foundation is the only voluntary health organization dedicated to education and research into osteoporosis. In that capacity, NOF currently administers the only privately funded research into this condition. Based on that experience, it is clear that the ability to address research of the scope required cannot be funded by the private sector alone. The need is too great.

Thus, on behalf of the millions of individuals with osteoporosis and their families, we urge you to take a strong stand by making a commitment commensurate with the magnitude of this public health threat. Consistent with that view, we urge that research be targeted into the four principal areas as identified in the 1984 Consensus Development Conference on Osteoporosis sponsored by NIH:

1) Basic, epidemiological and clinical studies to determine the mechanisms of and risk factors for osteoporosis and to predict responses to intervention;

2) Studies to expedite the improvement of existing methods for measuring bone tissue and for developing newer and less expensive approaches;

3) Studies to develop safe, effective, and low cost approaches for preventing osteoporosis; and

4) Studies to cure osteoporosis.

Again, I want to thank you for the opportunity to express our views on these issues of great concern.

OSTEOPOROSIS

Senator **Adams**. I have one question, and I completely agree with your analysis of the healthy person that breaks the hip—all of us has had this happen in families. We see it all the time.

What things can individuals do through either their lifestyle or other changes to prevent it. You will see side by side, two people, one looking very frail but really quite sturdy, and another that looks quite sturdy but breaks a bone and it never heals. Is this connected to diet or exercise or, well, you just tell me?

Dr. **Riggs**. We certainly need more research to target better the susceptible person for osteoporosis. We do know a lot, however, of general measures in the environment that make a difference. Certainly, exercise is good for bone, smoking increases the risk of osteoporosis by a factor of two. Hard to believe it, but here is one more thing that smoking does that's bad.

Alcohol abuse is another problem, inactivity. We know that menopause is important, and we know that much of the bone loss following the menopause can be prevented by estrogen therapy, and there is more and more evidence that calcium intake and calcium nutrition is important as well.

So, with the right kind of public health and educational programs, as happened in heart disease, and with more money to understand the basic mechanisms of bone, I am really very optimistic that this is one disease we can put behind us in the near future.

Senator **Adams**. Thank you very much, Doctor, for your testimony.

STATEMENT OF CARLO MAINARDI, PRESIDENT, AMERICAN COLLEGE OF RHEUMATOLOGY

ACCOMPANIED BY MARY MARTIN, ARTHRITIS PATIENT

Senator **Adams**. Our next witness is Dr. Carlo Mainardi, president of the American College of Rheumatology, accompanied by Mary Martin of Nevada, IA. And Senator Harkin sends his best regards and welcome from both himself and the committee.

Dr. **Mainardi**. I am a professor of medicine at the University of Tennessee. I appear before you today on behalf of the American College of Rheumatology, an organization of physicians and scientists engaged in arthritis research, education, and patient care. With me is Mrs. Mary Martin, a patient with rheumatoid arthritis from Nevada, IA. We ask your support for increased funding for the National Institute of Arthritis and Musculoskeletal and Skin Diseases, NIAMS.

Arthritis affects one in seven people. The costs of arthritis care are far greater than the proposition of Federal funds we have committed to solving the problem. Relative to national budgetary expenses, we believe that there is no problem which is as underfunded as arthritis.

Mrs. **Martin**. I was diagnosed rheumatoid arthritis 27 years ago. I have lived with it nearly half my life, and it has drastically changed my lifestyle. I no longer am able to practice nursing or participate in sports or go dancing, entertain our friends in our home with gourmet prepared meals.

I now serve more casual fare. If I am going to cook or bake, cooking supplies and utensils may need to be lifted from cupboards and bottles opened, and someone needs to be present to remove hot dishes from my oven. I need help with much of my homework.

If I plan to leave the house alone to do errands, shop, or visit friends, it is necessary for me to eyeball my destination. If there is a step or curb, a handrail is necessary. Is the door heavy glass? If so, it may be too difficult for me to open. Is the approach or sidewalk flat? Even a slight incline can be dangerous for me.

We have raised five children. At times the responsibility and the workload was most trying, as I dealt with the pain and fatigue of RA. I have been fortunate to have a cooperative family and a husband who, more often than not, anticipates my needs. It is the day-to-day fluctuations and the dramatic swings from feeling energetic to the extreme fatigue that is difficult. Will I be on my feet tomorrow, or will I be too stiff and sore to accomplish much of anything.

My treatment, to date, has included major surgery on multiple occasions, and virtually every drug available has been tried. Each one has either lost its effectiveness or has caused serious side effects. Right now, I am pretty close to the end of the line of available drugs. If the drug I am currently using fails, will there be a rescue drug for me? It is necessary that research continue so that new and safer drug treatments can be developed for people in my predicament.

Dr. MAINARDI. There is a direct relationship between research and better health care. Funding levels have declined throughout the NIH, and this has reached crisis proportions at the NIAMS. Despite the high costs of arthritis care, the NIAMS now receives only 2.2 percent of the total NIH budget. Under the administration's request for fiscal year 1991, NIAMS will be able to support 19 percent fewer research grants than it did in fiscal year 1989. In the current year, less than one in six approved applications is receiving funding, and this is expected to decline in 1991.

PREPARED STATEMENT

The ACR is joining hands with other professional and voluntary organizations in support of a $50 million increase for the NIAMS in the fiscal year 1991 appropriations bill. We hope you will be supportive of this initiative.

We both thank you for listening.

[The statement follows:]

STATEMENT OF CARLO MAINARDI

The American College of Rheumatology (ACR) is an organization of physicians and scientists dedicated to providing leadership in arthritis research, education and patient care. Last year, the College presented the subcommittee with some startling facts about arthritis, a disease that is present in 1 in 7 people, and which in some way affects 1 out of 3 families. Some of the most important facts had to do with the high costs of arthritis and other rheumatic diseases — in economic terms, as well as in terms of the impact on the quality of life of those who have these diseases. For example:

- Arthritis is the second most common chronic illness in the United States.
- The total costs of all types of arthritis are over *$25 billion each year*, including medical costs and costs resulting from lost income and reduced productivity.
- Rheumatoid arthritis, a severely crippling form of arthritis affecting between 1 and 2 percent of the population, is responsible for significant health care costs.
  In California, the government's insurance program (the Medi-Cal program) estimated that total health care costs for people who have RA are *three times* higher than for those who do not have the disease.
- About 60 percent of people with RA under age 65 who were employed at the onset of the disease become work disabled. On average, people who have RA earn only 50 percent of their predicted income. The "earnings gap" attributable to RA among men and women of working age is estimated at *$6.5 billion each year*.

New information shows that the economic costs may increase still more if corrective action is not taken: For example, we know that, on average, our population is aging. An article in the January Journal of the American Medical Association examining chronic conditions in those aged 60 years and older, found arthritis in 49 percent of the study population, much more common than was previously thought. Extrapolated to the estimated United States population in this age bracket, arthritis probably affects over 16 million people aged 60 and older, now. The number of individuals affected (as well as associated costs) may increase as the size of our over 60 population continues its upswing. At this rate, it is expected that these disorders may account for more than $95 billion in health-care costs by the year 2000.

In the elderly population, there is an increased likelihood that an individual will have two or more chronic conditions, and there is an association between the number of conditions present in one person and the occurrence of disability. The provision of care to people who are in some way disabled also contributes significantly to increased financial costs to the government, private insurers, and to society as a whole. Because the number of conditions present may represent a useful measure of the burden of illness in older persons, the JAMA article concludes, "disability prevention should be a part of our public health strategy." We agree, but would add that, especially in light of the imperative to address this nation's escalating health-care costs, an adequate research investment also should be a part of our public health strategy.

Last year, ACR set out some of the research which is being conducted in the area of arthritis and other rheumatic diseases, the results of which have the potential to reduce the high economic costs as they lead to achieving improved management, and better treatments, and ultimately cures for these diseases. In other words, we made the case that medical research is *cost-effective*. It is only this year, however, that in light of these facts, ACR comes before you with the specifics of a *workable plan* to address the problem:

Proposal to Reduce Health Care Costs to this Nation which are Attributable to Arthritis & Related Diseases:

1. Identify areas of research opportunity

There are several areas of promise within the field of arthritis research. We need to continue efforts to identify and prioritize areas where we are coming closer to advances in treatments which will impact health care costs.

Gout is an example of a disease where cost reductions can be counted as a result of improved management strategies developed through scientific research. Appropriate drug therapies significantly limit damage to the joints, so that mobility is maintained and pain is alleviated. Most individuals with gout can continue active and productive lives, and can remain in the workforce, contributing to the economy. Extremely few require costly on-going care.

For other rheumatic diseases, more will have to be accomplished before long-term health care cost savings can be realized to any large extent. The devastating disease lupus represents an exciting opportunity for which research should be stepped-up, so that advances in treatment and therapy can be achieved to better address this disease and to help reduce the high economic burden associated with it.

The NIAMS has done an excellent job of identifying other areas of opportunity in the arthritis and rheumatic disease field. The ACR has contributed to the institute's efforts in this regard through NIAMS' advisory bodies, participation in symposia sponsored by the institute, and through on-going informal discussion. In addition, the ACR recently compiled materials outlining several areas of opportunity in the rheumatic diseases. Issues which have great scientific promise include T-cell suppression, antigenic mapping and definition of cytokine structure and function. While certainly not intended as an inclusive listing, we believe that accelerating scientific inquiry in these, and several other areas is warranted, as the results of such research will form the foundation for better management and therapies, bringing associated health-care cost reductions.

2. *Fund an accelerated research agenda*

Even though the NIH has always been looked to as the flagship institution for science, and as the training ground for our future scientists, currently all medical research funded by the government is outpaced by private industry and pharmaceutical companies. Far from suggesting that we should adopt an attitude of complacence, this fact signals real trouble for the future of science, since the lion's share of pharmaceutical spending for "research and development" is on the development side, and not on basic research. Without adequate support for research from the federal government, our future ability to make the advances which can lead toward improved health, and which will contribute to reduced health care costs—is jeopardized. It is also worth noting that about one-half of private industry's spending in pharmaceutical R&D is aimed at conditions primarily affecting those over age 65—an increasing portion of our population. Unless reversed, the insufficient level of federal support directed toward diseases affecting the elderly—such as arthritis—will result in increased health care costs, as older people increasingly may have to be consigned to costly custodial care.

Especially in light of the potential to contribute to efforts which will reduce health-care costs, federal support for arthritis and rheumatic disease research at the NIAMS should be increased. However, we feel that the benefits of this strategy have not been fully recognized in the funding decisions made to date: Ever since it was established as a separate institute in 1987, the NIAMS has been able to fund a smaller percentage of the grants it receives than virtually every other institute within the NIH. Even though the costs of treating arthritis and other diseases falling within the NIAMS' mandate have been demonstrated to be extremely high, the NIAMS now receives only 2.2% of the total NIH budget. Currently, the NIAMS can support only 1 in 6 of its approved grants, compared with 1 in 4 for NIH as a whole. Under the Administration's request for NIAMS for fiscal year 1991, the situation has not been corrected, and in fact funding constraints are worse than ever for this institute: It would be able to support only 150 new and competing research grants—this is *19 percent* fewer than in fiscal year 1989.

Congress should provide a "lump-sum" increase of about $50 million so that this institute will be able to fund more of the high-quality proposals within its broad research mandate. With the right kind of federal involvement and support for arthritis research, we can anticipate important advances in care and treatment, and we can also expect to win health care cost-savings and an improved quality of life for people who have these diseases.

3. *Provide mechanism to ensure that research advances and associated cost-savings can be on-going*

Continued advancement in any area of biomedical research is contingent on having a solid core of well-trained scientists in the field. For many years, this nation has relied on having this core in place, but this reliance is not realistic for the future, based on the existing funding trend. As bright young researchers see that extremely high quality proposals are consistently not funded, they become more and more likely to choose other careers. The scientific advances we have today are the result of the era during which we had no trouble attracting the brightest students into research. Future advances are jeopardized by the current climate in which funding constraints make research careers less attractive to the very people we need most to attract. Adequate funding for research training activities is essential. Several committee members have taken a justified interest in the unrealistically low stipend levels afforded post-doctoral trainees, especially given the fact that research fellows usually have education loans to repay and may have family support obligations, as well. We strongly agree that financial problems contribute to the emerging crisis in retaining young scientists committed to a research career, and believe that stipend levels should be brought up to a more realistic level. Beyond this, our proposed overall funding level for the NIAMS should be implemented. Providing better support for new and competing research grants — which are especially important to new researchers just entering the field, will positively impact the current crisis situation facing first time grantees.

Conclusion

Congress should look upon the initiative to increase funding for the NIAMS as an opportunity to reduce the high economic costs associated with the occurrence of arthritis and other rheumatic diseases. Given the importance of long-term cost savings to society which can be achieved if this plan is followed, the ACR believes that continued reliance on previous conceptions about federal funding for research may be misguided, and might be characterized as "penny-wise but pound foolish".

Arthritis research is cost-effective. While arthritis and related diseases cost our nation more than $25 billion each year, we do have the potential to reduce the costs through research. Biomedical research efforts yield improvements in treatment for patients and better management strategies. As such advances are made, costs of insurance and other costs borne by the government—including costs associated with long-term care and worker's compensation—will significantly decline. The "up-front" investment in research is what is needed to get a workable "cost-savings plan" rolling.

We have presented this strategy to you with full awareness of concerns about our national deficit, and the associated budgetary constraints facing the Congress. Because an appropriate federal investment in biomedical research will greatly reduce costs to society in the long run, we believe that the initial—relatively small—investment for arthritis research is more than warranted.

Over the last few years there has been increasing *recognition* of the benefits of strengthening support for domestic discretionary programs. But this year, with world events beginning to move in a direction which might allow for gradual defense funding reductions, there exists a unique opportunity to be able to take the next logical step—a step in the direction of long-term health-care cost savings. One very important part of that "next step" should be *action* in the form of providing a lump-sum increase for NIAMS research.

Thus, our primary recommendation directed to the appropriations committees centers around a $50 million increase for the NIAMS in FY 91. The resulting funding level would not be anywhere near sufficient to fully support *all* the scientifically sound research which exists within the purview of the NIAMS. It would be, however, enough to begin to support a more reasonable amount of the valuable research on arthritis and related diseases *which will be absolutely essential* if we are to achieve both long-term cost savings to society, and improvement in the quality of life for people with arthritis. We strongly support whatever efforts you can take to augment by $50 million the NIAMS' proposed funding level for FY 91. We appreciate the opportunity to provide the subcommittee with this information. The College stands ready to provide you with any additional information you may desire.

Senator ADAMS. Thank you. What is the reason for the decrease in small amount here. We have heard previous witnesses on arthritis. Is it a giving up in the feeling that additional drugs will be found, or is it just that it is going to happen, or do you have another reason or you just tell me what you think?

Dr. MAINARDI. I am not sure I understand the question.

Senator ADAMS. The question is, why is that you are not receiving more funding when this is a substantial portion of the population? We have heard several witnesses testify that, particularly as we are going to an older population now, we are going to have a staggering increase, and somebody called it an epidemic.

Dr. MAINARDI. I can only offer an observation and opinion. When our institute was created, it was created during a period of extreme physical austerity nationally, the net result of which is that we are one of the few, if not perhaps, the only new institute created at NIH that was worse off after it was created than it was before it was created.

Senator ADAMS. I see. Thank you very much, Doctor and Mrs. Martin. I appreciate your testimony.

STATEMENT OF CHRISTINE STEVENS, SECRETARY, SOCIETY FOR ANIMAL PROTECTIVE LEGISLATION

ACCOMPANIED BY WILLIAM CATTO

Senator ADAMS. Our next witness is Christine Stevens, secretary of the Society for Animal Protective Legislation.

Ms. STEVENS. Thank you, Mr. Chairman. I would like to bring with me, William Catto. I am asking William Catto to also join me in case there is a question that he can answer better than I.

Senator ADAMS. Thank you.

Ms. STEVENS. May I put my full statement in the record and just highlight it?

Senator ADAMS. Without objection, your full statement will appear in the record as though given.

Ms. STEVENS. Thanks very much. The Society for Animal Protective Legislation is very supportive of the National Institutes of Health's efforts to increase progress in the three R's: refinement, reduction, and replacement of inhumane animal experimentation. We urge sufficient funding for the NIH to continue making progress in the development of alternatives.

Refinement alternatives include measures such as pain alleviation in experiments through proper use of analgesics and, two, proper housing which will ensure the overall well-being of laboratory animals. We would like to see more progress made on the use of analgesics in NIH-funded research. They should use the standard that unless it is proven that the use of an analgesic would interfere with the research protocol, it should be used.

The refinement alternative of proper housing and husbandry is a priority on which NIH is beginning to work through the Division of Research Resources. NIH funds grants for upgrading of laboratory animal facilities and we have been very pleased to work with NIH to improve their requests for grant applications for this program. The 1991 request for applications will now include a requirement that the institutions or individuals seeking funding must describe the ways in which the improvement to the animal facility will improve the animal's welfare. And we urge that you appropriate at least $35 million for this program.

For continued progress and reduction and replacement alternatives, we urge a funding of $13 million for NIH's alternatives program, as administered by the Biological Models and Materials Resources Program of the Division of Research Resources.

The congressionally mandated alternatives plan has not made the progress anticipated due to the lack of funding within NIH. Micro-organisms, cell and tissue cultures, mathematical computer modeling, of which we have heard a good deal already with other witnesses, need to be pressed forward. The long-delayed regulations for part 3 of the Improved Standards for Laboratory Animals Amendments, passed by the Congress in 1985 are due, at last, to be made final. Not, however, without reproposal of the standards for two of the provisions of the law: opportunity for exercise for laboratory dogs, and a physical environment adequate to promote the psychological, well-being of nonhuman primates, to quote from the language of the statute.

It is essential that the will of Congress should be respected in these final regulations. They must not be undermined through pressure by those interests who sought, unsuccessfully, to prevent passage of these amendments to America's chief animal welfare law.

This distinguished committee's influence is needed to ensure the honorable outcome that the American public expects and deserves. It strongly supported these modest necessities for humane treatment of primates, our closest relatives in the animal kingdom, and dogs, our best animal friends. We owe it to these animals who give their lives for us, and the least that we can do is make their brief lives in the service of science, endurable. Please use your good offices to see that the dogs and primates get a square deal, an honest return for their sacrifice.

[The statement follows:]

STATEMENT OF CHRISTINE STEVENS

The Society for Animal Protective Legislation is very supportive of the National Institutes of Health's efforts to increase progress on the "3R's": Refinement, Reduction, or Replacement of inhumane experimentation. We urge sufficient funding for the NIH to continue making progress in the development of alternatives.

Refinement alternatives include measures such as (1) pain alleviation in experiments through the proper use of analgesics and (2) proper housing which will ensure the overall well-being of laboratory animals. We would like to see more progress made on the use of analgesics in NIH funded research. The NIH should use the standard that unless it is proven that the use of an analgesic would interfere with a research protocol, all NIH funded research will employ therapeutic levels of analgesics.

The refinement alternative of proper housing and husbandry is a priority for which NIH is beginning to work. Through the Division of Research Resources, NIH funds grants for the upgrading of laboratory animal facilities. We have been very pleased to work with NIH to improve the request for grant applications for this program; the 1991 request for applications will now include a requirement that the institution or individual seeking funding must describe the ways in which the improvements to the animal facility will improve the animals' welfare. We applaud this step by NIH to encourage facility design for maximum benefit to the animals. We urge the subcommittee to appropriate at least $35 million for the program.

For continued progress on reduction and replacement alternatives, we urge funding of $13 million for NIH's alternatives program, as administered by the Biological Models and Materials Resources Program, Division of Research Resources. The Congressionally mandated alternatives plan has not made the progress anticipated due to a lack of funding within NIH. The Biological Models and Materials Resources Program will be vital in promoting studies of microorganisms, cell and tissue culture systems, mathematical and computer modelling, and chemical and physical assays which can reduce the numbers of animals used, either by supplementing or amplifying the results of animal research, or by replacing the use of animals altogether. We hope you will recommend that $13 million be directed towards this program.

Vigorous pursuit of all three "3R's", Refinement, Reduction and Replacement, is essential for progress in science and advancement of the humane care of animals in research laboratories. The National Research Council, in its recent publication. Opportunities in Biology, states: "As a result of these (cellular) techniques, of powerful computers, and of imaginatively constructed new instruments, all fields of biology are being revitalized. The methods necessary for a complete understanding of living systems at the molecular level now seem to be at hand. We have already learned a great deal about how the structures of proteins determine their functions in living cells, and we shall learn a great deal more during the next few years, provided that we continue to support these efforts adequately. Discoveries of structure-function relationships are of fundamental importance for understanding all of the interactions within biological systems, from the determination of our ability to resist infection, to our understanding of the way a fertilized egg develops into an adult human, to the very ways we dream, imagine, and reason. Biology holds the key to understanding these and all other processes-fundamental to life."

Alternatives, far from being a smokescreen as some nay-sayers would have it, are in reality, central to the future of science and essential for the welfare of animals in laboratories. We are glad to have cooperated with NIH in the two areas for which we are requesting increased funding support. We hope that this cooperative atmosphere can continue to grow and that the efforts of some individuals to create a hostile, oppositional atmosphere will not succeed.

The long delayed regulations for Part 3 of the Improved Standards for Laboratory Animals amendments passed by the Congress in 1985 are due to be made final at last, not, however, without reproposal of standards for two provisions of the law: The opportunity for exercise for laboratory dogs and "a physical environment adequate to promote the psychological well being of non-human primates" to quote the language of the statute. It is essential that the will of Congress be respected in these final regulations. They must not be undermined through pressure by those interests who sought unsuccessfully to prevent passage of these amendments to America's chief animal welfare law.

This distinguished subcommittee's influence is needed to ensure the honorable outcome that the American public expects and deserves. It strongly supported these modest necessities for the humane treatment of primates, our closest relatives in the animal kingdom, and dogs, our best animal friends. We owe much to these animals who give their lives for us. The least we can do in return is to make their brief lives in the service of science endurable. That means they cannot constantly be imprisoned in small cages, where many of them develop unnatural aberrations—stereotypies, to use scientific phraseology. It is our plain duty, as the Congress recognized in passing the Improved Standards for Laboratory Animals amendments to the Animal Welfare Act. Please use your good offices to see that the dogs and primates get a square deal—an honest return for their sacrifice.

HUMANE TREATMENT OF ANIMALS

Senator **Adams**. Thank you very much for your testimony. The society does seem pleased with the progress NIH has made in more humane treatment of animals.

You have recommended $13 million for NIH's Biological Models and Material Resources Program. Will that amount be sufficient to fund the studies supplementing animal research or replacing animals in research as biological models?

Ms. **Stevens**. Well, I would not like to say it is sufficient, because there is a very big area out there, as other people have testified, is growing enormously right at this very time. And you, Mr. Chairman, were talking particularly about use of computers to get all the information together. And NIH is doing some of that, but we would be perfectly happy if you gave them some more for that purpose.

Senator **Adams**. Thank you very much, both of you, for your testimony. We appreciate it.

STATEMENT OF MARK SPERLING, UNIVERSITY OF PITTSBURGH SCHOOL OF MEDICINE, ON BEHALF OF THE PUBLIC POLICY COUNCIL

Senator **Adams**. Our next witness is Dr. Mark Sperling, University of Pittsburgh School of Medicine, Public Policy Council.

Dr. **Sperling**. Good afternoon, Senator Adams, and thank you for the opportunity of presenting for you. The Public Policy Council that I represent, is actually a coalition of the Society for Pediatric Research, the American Pediatric Society, and the American Medical School Departments of Pediatrics Chairmen.

In view of the fact that some of the information I was to present has already been given to you in different forms, I would like to submit the entire record and highlight some of the statements.

Senator **Adams**. Without objection, your entire statement will appear in the record as though read, and you may proceed as you outlined.

Dr. **Sperling**. Thank you. Mr. Chairman, I am Mark Sperling, chairman of the department of pediatrics at the University of Pittsburgh School of Medicine and pediatrician-in-chief at the Children's Hospital of Pittsburgh. I represent the American Pediatric Society, the Society for Pediatric Research, and the Association of Medical School Pediatric Department Chairmen. These organizations represent pediatric researchers, the faculty of medical and research facilities, and pretty much the leaders of all of U.S. medical school pediatric departments.

I come before this committee to ask you to keep uppermost in your minds the needs of our infants, children and adolescents during your appropriations deliberations for fiscal year 1991. Biomedical and behavioral research covering all aspects of human development, both normal and abnormal, and on environmental and societal influences on our children and their families will help those of us who care for and care about those children. Such research helps us to understand their needs and thereby improve the services and treatments that we provide.

I wish to express the concern of the pediatric biomedical research community over the current practice of imposing downward-negotiated reductions on each competing grant. This is a theme you have heard before, and I do not wish to belabor it.

Another critical source of support for many researchers, especially new investigators, is the biomedical research support grant program. This programs provides crucial funding for new research, and it supplies bridge funding during the transition period between grant support. We ask you to restore the biomedical research support grant program to its fiscal year 1989 level of $56 million.

The President's budget request of $7.93 billion does not allow for growth in the NIH program. Our organizations collectively, strongly urge this subcommittee to adopt the recommendations of the ad hoc group for medical research funding of $9.273 billion for NIH.

Now, last year, the NICHD, the National Institute of Child Health and Human Development, was urged to consider establishing a program to fund child health research centers. I am glad to report that NICHD has issued a request for applications for these centers, and that the pediatric research community has greeted this program with enthusiasm and excitement.

In order to build upon opportunities now before us, this funding will provide core support to academic and clinical centers whose primary mission is the care of children. This support will enable these centers to build upon existing research and training programs and to branch out into new areas as needed. But most importantly, this money will provide critical support for pediatricians embarking on their research careers.

We urge this subcommittee to provide sufficient moneys to NICHD to allow for this program to grow into maturity. For NICHD, our recommendation is a funding level of $635 million, which would allow NICHD to increase the Child Health Research Center Program, as well as to vastly improve its funding rate and eliminate the downward negotiations it currently takes.

Finally, I want to turn to the training of health professionals. Once again, the administration has chosen to eliminate funding for the training of many health professionals, with the exception of some programs to encourage funding for the training of minorities. At the time when so many children lack medical attention from the pediatrician or from any child health care professional, it seems unwise for the administration to adhere to a policy which appears to state that primary care physicians training is not important enough for Federal support.

Training facilities need continued assistance from outside sources, and the title VII primary care training grants, although a relatively small amount, is one of those sources. We urge this subcommittee to support the title VII care training grant program for general pediatrics and general internal medicine at its full authorization rate of $23 million.

Finally, we ask you to provide sufficient funding for the National Health Service Corps to allow the program to operate both the scholarship and loan repayment programs. Establishing and funding the loan repayment program did not eliminate the need for scholarships, especially for the minorities. Many minorities who wish to become part of the National Health Services Corps cannot obtain the initial funding to attend medical school, and so they need this scholarship funding.

Thank you for the opportunity to present on behalf of all the children in the United States.

[The statement follows:]

STATEMENT OF MARK A. SPERLING

I am Dr. Mark Sperling, Chairman of the Department of Pediatrics at Children's Hospital of Pittsburgh and the Vira I. Heinz Professor of Pediatrics at the University of Pittsburgh School of Medicine. Today I represent the American Pediatric Society, the Society for Pediatric Research and the Association of Medical School Pediatric Department Chairmen. These organizations represent pediatric researchers, the faculty of medical and research facilities, and the leaders of all U.S. medical school pediatric departments. My testimony will focus on biomedical and behavioral research and research training supported by the National Institutes of Health and the Alcohol, Drug Abuse and Mental Health Administration and on the training of our health professionals.

I come before this subcommittee to ask you keep uppermost in your minds the needs of our infants, children and adolescents during your appropriations deliberations for fiscal year 1991. Biomedical and behavioral research covering all aspects of human development, both normal and abnormal, and on environmental and societal influences on our children and their families will help those of us who care for and care about those children. Such research helps us to understand their needs and, thereby, improve the services and treatment we provide.

I NATIONAL INSTITUTES OF HEALTH RESEARCH AND TRAINING

The National Institutes of Health (NIH) is the premier institution of its kind and, unquestionably, one of our most famous assets. It supports, through intramural and extramural activities, biomedical and behavioral research conducted by a superior group of investigators. We must not allow the record of the NIH to be diminished.

Briefly, I wish to express the concern of the biomedical research community over the current practice of imposing downward negotiated reductions on each competing and noncompeting grant and on the various centers supported through NIH.Each grant's budget is critically reviewed several times prior to final approval. To have such a conscientiously prepared and examined budget cuty by nearly 20 percent (as is the case in some institutes) can be detrimental to the integrity of this nation's research enerprise. Such a practice is harmful not only to the short and long term planning of our research facilities, but it is discouraging to young investigators looking towards a career in biomedical or behavioral research.

Another critical source of support for many researchers, especially new investigators, is the Biomedical Research Support Grant program, a part of the National Center for Research Resources. This program provides crucial funding for several purposes. It can provide funds for new research and it supplies bridge funding during the transition period between grant support. We ask you to restore the Biomedical Research Support Grant program to its Fiscal Year 1989 level of $56 million.

The President's budget request ($7.930 billion) does not allow for growth in the NIH program. In fact, $8.321 billion would be required for NIH to support fully its current level of effort. Our organizations strongly urge this subcommittee to adopt the recommendation of the Ad Hoc Group for Medical Research Funding of $9.237 billion for NIH.

Last year Congress directed the National Institute of Child Health and Human Development (NICHD) to consider establishing a program to fund Child Health Research Centers. I am glad to report that NICHD has issued a Request for Application for these centers and the pediatric research community has greeted this program with enthusiasm. In order to build upon opportunities now before us, this funding will provide core support to academic and clinical centers whose primary mission is the care of children. This support will enable these centers to build upon existing research and training programs and to branch out into new areas as needed. But, most importantly, this money will provide critical support for pediatricians embarking on their research career. We urge this subcommittee to provide sufficient monies to NICHD to allow for this program to grow into maturity.

NICHD is the only institute designed to focus primarily on infants, children, adolescents, pregnant women, and families. As such, it supports investigator-initiated projects and centers which are vital to the future of this entire nation. Such projects and centers include research in infant day care, pediatric AIDS, injury prevention, mental retardation, learning disabilities, contraception, fertility, and Sudden Infant Death Syndrome (SIDS). For NICHD, our organizations recommend a funding of $635,306,000. This would allow NICHD to increase the Child Health Research Center program as well as vastly improve its funding rate and eliminate the downward negotiations it currently takes from each grant and center award.

Research relevant to infants, children and adolescents is not the sole province of NICHD. Other institutes, organized along more a more categorical, disease-oriented, structure have always supported significant pediatric research. The missions of most institutes transcends age. As pediatricians, we ask you to support a new proposal which would direct the National Institute of Diabetes and Digestive and Kidney Disease to increase attention to the needs of children with kidney diseases -- specifically, to create at least two centers for pediatric nephrology. This field has grown rapidly in both technology and expertise over the past 20 years, but there is much to be learned. It is important for such a promising area of research not to be ignored.

II ALCOHOL, DRUG ABUSE AND MENTAL HEALTH ADMINISTRATION RESEARCH

In our society, with all its varied harmful influences on our young children and adolescents, the research supported through the Alcohol, Drug Abuse, and Mental Health Administration (ADAMHA) becomes increasingly more important. Children today see their parents, other elders, and their peers addicted to alcohol, cocaine, heroine, and crack cocaine. Many of them grow and develop in a home and neighborhood environment that is cruel. This is true for many children in all socio-economic levels. It is not surprising, therefore, to learn that perhaps as many as 7.5 million children and adolescents have serious mental and emotional disorders. As pediatricians we must join with other child advocates in urging you to direct ADAMHA to initiate a National Plan for Child and Adolescent Disorders, with $60 million to begin such a plan.

For ADAMHA research overall, we support the Ad Hoc Group for Medical Research Funding's recommendation of $1.197 billion for research and training.

III TRAINING OF HEALTH PROFESSIONALS

Once again, the Administration has chosen to eliminate funding for the training of many health professionals, with the exception of some programs to encourage funding for the training of minorities. At a time when so many children lack medical attention from a pediatrician, or from any child health care professional, it seems unwise for the Administration to adhere to a policy which appears to state that primary care physician training is not important enough for federal support. The training of pediatricians and other primary care physicians is not one of the more lucrative operations of any institution; pediatric procedures do not bring in the same level of revenue. This does not mean such training is unimportant. It does mean that training facilities need continued assistance from outside sources, and the Title VII primary care training grants, although a relatively small amount, is one of those sources. We urge this subcommittee to support the Title VII primary care training grant program for general pediatrics and general internal medicine at its full authorization level of $23 million.

We also ask you to provide sufficient funding for the National Health Service Corps to allow that program to operate both the scholarship and loan repayment programs. Establishing and funding the loan repayment program did not eliminate the need for scholarships, especially for the minorities. Many minorities, who wish to become a part of the National Health Service Corps, cannot obtain the initial funding to attend medical school, and so need the scholarship funding.

Senator ADAMS. Thank you. What level of funding would you believe would provide sufficient funding for the National Health Service Corps Program to operate both the scholarship and loan repayment program?

Dr. SPERLING. The full funding that we requested, I believe, was $23 million.

Senator ADAMS. And in your testimony you discuss the need for two new centers for pediatric nephrology. What is the funding level that you would believe would be necessary for NIDDK to establish those two centers for pediatric nephrology?

Dr. SPERLING. It is quite common to expect a funding level of about $1 million per center, so we would need about $2 million for those centers and the child health research center initiative has been funded to the tune of $2 million at the present time, which is enough funding for four to five centers at a rate of $400,000 to $500,000, and we would like to see that program built up to its full amount of $20 million, which would allow about 40 centers, or about one-third of all the medical schools in the United States, to have the capability of training young researchers to go on with the mission that's been so evidently spoken about today.

SUBCOMMITTEE RECESS

Senator Adams. Thank you very much, Doctor. Thank you for your testimony. The subcommittee thanks all of those who have testified here today, for their testimony.

The subcommittee will stand in recess until 9 a.m., Wednesday, March 28, when we will meet in SD–192 to continue our public witness hearings on the administration's fiscal year 1991 budget request.

[Whereupon, at 12:40 p.m., Tuesday, March 27, the subcommittee was recessed, to reconvene at 9 a.m., Wednesday, March 28.]

DEPARTMENTS OF LABOR, HEALTH AND HUMAN SERVICES, AND EDUCATION AND RELATED AGENCIES APPROPRIATIONS FOR FISCAL YEAR 1991

WEDNESDAY, MARCH 28, 1990

U.S. SENATE,
SUBCOMMITTEE OF THE COMMITTEE ON APPROPRIATIONS,
Washington, DC.

The subcommittee met at 9:36 a.m., in room SD-192, Dirksen Senate Office Building, Hon. Daniel Inouye presiding.

Present: Senator Inouye.

NONDEPARTMENTAL WITNESSES

OPENING REMARKS OF SENATOR INOUYE

Senator INOUYE. Good morning.

This morning we continue the fifth of 6 days of public witness testimony focusing on programs funded by the Subcommittee on Labor, Health and Human Services.

During these several sessions the subcommittee will receive testimony from 150 witnesses. As a matter of regret to all members of the subcommittee that we have had to limit the number of witnesses that we are able to hear this year.

You have all been very understanding about our time constraints. And I do want to assure that witnesses who have their testimony submitted to the staff will have that testimony put in the record.

As we all know based on the letter you received from Chairman Harkin each witness has a limited number of minutes in which to present his or her oral testimony. I will not use these lights here, but out of courtesy to all those who are here to testify, please be as brief as you can. And this will give us some time to question or for discussions.

STATEMENT OF HON. JOHN McCAIN, U.S. SENATOR FROM ARIZONA

Senator INOUYE. I would like to welcome all of you to this special meeting of the committee. And our first witness this morning is a very distinguished member of the U.S. Senate. He is my colleague from the StaTe of Arizona, Senator John McCain. Senator McCain also serves as the vice chairman of the Select Committee on Indian Affairs. And this morning I am certain that he will present the testimony for that subcommittee.

Senator McCain.

Senator McCain. Thank you very much, Mr. Chairman.

And I will try to be brief, because if there was ever an example of preaching to the choir, that is certainly the case when I discuss native Americans' issues with you.

Under your leadership and with the rest of the committee, I think we have made enormous advances and changes and done a great deal for American Indians, but clearly there is a lot more that we have to do. And, Mr. Chairman, wearing your other hat, I am deeply appreciative of your concern and sympathy over the budget issues concerning native Americans.

Mr. Chairman, I have a written statement I would request to be made part of the record plus a study that the select committee has made that is a careful analysis of the historic trends in Federal funding for Indian programs and services.

Senator Inouye. Without objection the full statement will be made part of the record. And I, if I may, I wish to be associated with your statement, sir.

Senator McCain. Thank you, Mr. Chairman.

Very briefly, in the last 10 to 15, 20 years, the eligible Indian service population has nearly doubled. Twice the number of eligible native Americans exists today as 20 years ago. And yet, the real per capita funding for native Americans has decreased, and decreased significantly.

So we not only have a real funding problem as far as amounts of money devoted to native Americans, our poorest citizens, but we also have a dramatic and explosive increase in the number of eligible native Americans.

Mr. Chairman, in the area of health, Indian and native people suffer a higher rate of disease and alcoholism than any other segment of our population. The rate of diabetes and diabetes associated complications is at least five times higher for native Americans than the rest of the population.

In some areas of Indian country, as you well know, Mr. Chairman, fetal alcohol syndrome affects 8 out of every 10 babies. The rate of suicide among Indian youth far exceeds the national average. It will take nearly 13 years at current funding levels to meet the backlog of necessary construction of health facilities in Indian country. That is a backlog of nearly $500 million.

I just would like to talk about three areas that fall under this committee's jurisdiction. In the area of education we clearly need an increase of impact aid funds for students who live and work on Federal or Indian lands. We need to increase the level of spending for the administration for native Americans. I am proposing that we raise it from $13.7 million to $45 million. We clearly need an increase in the funding for the JTPA Partnership Act and for the JTPA summer youth program.

Mr. Chairman, I will summarize. We as a Nation have failed in our obligation to native Americans. And those obligations were consummated by solemn treaties. Your and my deep regret is that we cannot get the attention of the American people or their representatives to address these compelling issues that face us.

I do not come before you, Mr. Chairman, with answers to many of the problems that face native Americans. I wish that I could.

But I do know that if we continue to deprive them of funds in real terms for basic human needs, then the condition can only worsen. And we as a nation, frankly, we will have our national honor stained to some degree, because we have failed to fulfill those obligations.

And so, Mr. Chairman, I hope that the committee would consider some increases in some fundings for programs that I pointed out and in other areas as well.

Thank you, Mr. Chairman. And I want to again express my deep appreciation to you for your leadership, for the time you have spent traveling all over this Nation in Alaska and Hawaii in addressing the needs of America's first citizens.

Senator INOUYE. I thank you very much, Senator McCain.

I would like to tell the group gathered here that Senator McCain and I have assumed for ourselves a certain commitment and responsibilities that are not the most popular in the U.S. Congress.

It may be well if I expanded upon the Senator's statement and just give you a few examples. We spoke of treaties. In the 200 years that we have had relations with the Indians—and incidentally native American Indians are sovereign. Their reservations are sovereign as the city of Washington. And as such we have a relationship based on treaties as we do with the Soviet Union, Great Britain, or France.

Over the years we have entered into 800 treaties with Indian nations and tribes. Of these 800 treaties, 430 are languishing in our files in the U.S. Senate, because our predecessors just refused to consider them. Although we insisted that the Indians live up to their commitments as set forth in the treaties, we ratified 370 of these 800 treaties. But history shows that over the years, we proceeded to violate provisions in every one of them.

And here we are a nation that prides itself for living up to treaty commitments. But in the case of Indians, our record is a dismal one; 200 years ago anthropologists suggest that there were more Indians than you find today. Some suggest as high as 50 million native American Indians in the lower 48 States.

Today the number has dwindled to about 2 million. In those early days, we recognized the sovereignty and title held by Indians in 550 million acres of land. Today they have title over 50 million acres of land. Somewhere along the way as a result of violation of treaties for one thing, they lost about 500 million acres of land.

The health conditions as set forth by Senator McCain is not only dismal, but I think it is a national disgrace. For example, in Alaska where we have Eskimos and other Aleuts and Indians, the suicide rate among young men between the ages of 20 and 23 is 14 times the national norm. The alcoholism is at least seven times the national norm. If you happen to be a native American Indian and you have reached the age of 50, the odds are you have diabetes.

Now these are the dismal stories. Most of us take for granted the fact that we have running water and electricity in our homes. Over 23 percent of Indians do not have either one of them.

So we have much to do and we have an obligation and a trust responsibility which over the years we have failed to live up to. Senator McCain and I are going to change this. I thank you very much, sir.

Senator McCAIN. Thank you very much, Mr. Chairman.

STATEMENT OF DAVID IHA, PROVOST, KAUAI COMMUNITY COLLEGE, KAUAI ISLAND, HI

Senator INOUYE. Our next witness is the provost of the Kauai Community College from the Island of Kauai and the State of Hawaii, the Honorable David Iha. Mr. Provost.

Mr. IHA. Thank you very much, Mr. Chairman.

I am pleased to appear before this committee representing Hawaii's community colleges and sharing with you our collective efforts as well as those of Kauai Community College in particular, to meet the postsecondary needs of our native Hawaiian students. But before I do, I just wanted to add my personal thanks to the Senator for allowing me to be an intern back in 1974 on your staff, when I participated in the resource specialist program sponsored by the American Association of Community and Junior Colleges.

I think as a result of that experience I was able to gain a better understanding of our Federal Government. Also I want to publicly thank you for appearing on Kauai last August to give the commencement address to our special bachelors outreach program that we have coordinated with the school of nursing for the eight nursing graduates that we had last August.

The University of Hawaii community colleges is part of the higher education system of Hawaii under the governance of the University of Hawaii board of regions. And there are seven community colleges on four of the major islands. And the community colleges, they serve as the only access to many of our citizens.

The community colleges have an open admission policy. And as a result we try to provide maximum opportunities to the residents of Hawaii. But in spite of the open access policy that we have, I think we—I submit a chart that shows that underrepresentative groups of our native Hawaiians and Filipinos within our Hawaii's community colleges.

This is beyond access. I think we need to provide really sustained and coherent support services. We must look at teaching and learning processes, the curriculum and the campus climate so that we can increase the percentages of native Hawaiians entering our higher education system.

I think we need a new momentum that focuses on building communities. The American Association of Community and Junior Colleges recently issued a report prepared by the commission on the future of community colleges, which proposes the theme building communities become the new valuing point for the community college in America.

The commission which was chaired by Dr. Ernest Boyer defined the term community not only as a region to be served but also as a climate to be created. And I personally feel that the community colleges can create that kind of climate where we enhance our diversity within our system of community colleges.

I might just share with you some of the things that—a couple of cases where we have made an impact on native Hawaiians coming to the community colleges. On Kauai, in Niihau we have a very special group of native Hawaiians, the people of Niihau. Niihau sometimes called the forbidden island is located off the coast of

Kauai. And the people are all native Hawaiians who use the Hawaiian language as their only spoken and written language.

Our first graduate, our first male graduate that we had at Kauai Community College graduated last spring. He initially was recruited into our auto body repair program by counselor funded through our grant made possible by the Alu Like voc ed project. While he was in our auto body program, he also enrolled in adult basic skills program that was offered by Kamehameha Schools through another grant under the Carl Perkins Act. He later transferred into our welding program and graduated with a degree in welding.

He came to the college as a welfare recipient and left with basic skills, a marketable vocational skill and enhanced self-esteem. He is currently employed as a welder with one of our sugar plantations. Many of the agencies provided support through his semesters at the college. I think about the most crucial support was given through a caring faculty member who served as a mentor both in and out of the shop.

We are also proud of two women graduates from Niihau who graduated from our early childhood education program. One woman is a single parent with five children. She is currently a bilingual teacher working in the public elementary school to implement the Kamehameha elementary education program—a modern curriculum developed by the Kamehameha elementary administration school.

The other woman is the director of a Hawaiian preschool called Punana Leo, a family-based education center which receives support from the education for native Hawaiians programs.

I think we can move beyond providing early intervention through parent education groups. We can move beyond the vocational education programs. I think three of the community colleges with partnerships with our colleges and universities, we can be the connection to increase the transfer rates among native Hawaiian students.

And again let me share the story of one of our rare individuals. Ilei Beniamina was born on the Island of Niihau, her native tongue is Hawaiian. Her elementary school years were spent on Niihau. She later left Niihau and graduated from Kamehameha High School. She enrolled at Leeward Community College and then transferred to the University of Hawaii and Hilo, where she received a baccalaureate degree in Hawaiian studies. Today she is the first person from Niihau on the University of Hawaii payroll, serving as a counselor at Kauai Community College. She is also the first person from Niihau to receive a bachelor's degree.

She serves as an excellent role model for many of our native Hawaiian students who may have lost that vision that they too can succeed in higher education.

In closing let me just say that, I believe the establishment of native Hawaiian programs at each of our seven community colleges will serve as front-line institutions serving our native Hawaiian population and will demonstrate the institutional and governmental commitment to improving the numbers of native Hawaiians pursuing higher education.

PREPARED STATEMENT

I think we have a number of initiatives both at the local college level and within our State legislature. And we hope that through the leadership that is required by the campus leaders that we can change priorities, we can disrupt the status quo, and that we can serve all of our students, especially our underrepresented minorities.

Thank you.

[The statement follows:]

STATEMENT OF Y. DAVID IHA

I am pleased to appear before this committee representing Hawaii's Community Colleges and sharing with you our collective efforts as well as those of Kauai Community College in particular to meet the post secondary needs of our Native Hawaiian students from the islands of Kauai and Niihau. I am here to suggest that we initiate a new momentum for our Native Hawaiian students throughout our island state of Hawaii using the seven community colleges and the employment training office. A crucial first step in this new momentum is take a careful look at what we have done, what has worked, and, most importantly, what obstacles still remain in our paths.

The University of Hawaii Community Colleges, part of the public higher education system governed by the University Board of Regents, provide a two-year Associate in Arts undergraduate degree in general education and liberal arts and the Associate in Science degree and Certificates of Achievement and Completion in numerous vocational and technical fields.

There are seven community colleges - Hawaii Community College, Honolulu Community College, Kapiolani Community College, Kauai Community College, Leeward Community College, Maui Community College, Windward Community College, and the Employment Training Office. These Colleges are geographically dispersed on the four major islands of the State of Hawaii. The Colleges located on the island of Kauai, Maui and Hawaii are the only public higher education institution on the island and they provide the only access to educational opportunities for many of our residents living in small/rural communities outside of the main metropolitan center of Honolulu. Many of our Native Hawaiian population and our Filipinos, a recent immigrant group, live on the neighbor islands.

The Community Colleges serve a broad cross section of the population as a result of an "open admission" policy that permits any high school graduate or adult age 18 or older to enroll. This policy provides maximum educational opportunities to the residents of Hawaii. The Community Colleges enroll 21,000 regular credit students and another 20,000 students in special and non-credit programs during a typical semester. The average student age is 26 years, over half of the students attend school part time, with many working fulltime while attending classes. Women account for over half of the total enrollment, and the ethnic diversity of the Colleges generally reflects that of the community they serve except for the under-represented Native Hawaiians and Filipinos. The attached chart shows the under-represented Hawaiian/Filipino as a percentage of total enrollment in Hawaii's community colleges.

For these under-represented groups, we need a new momentum that provides more than access. Beyond the need for sustained and coherent support services, we must look at the teaching and learning process, the curriculum, and the campus climate. We must extend the traditional curriculum beyond western civilization to expose our students to the richness of our own multicultural heritage. We must look at the climate of our campuses to ensure that the atmosphere is one where we enhance and cherish our diversity. We must insure that the campus climate is one where our cultural events are routine and our students are welcomed with our version of Hawaiian hospitality. We must promote global perspectives among our grass roots students.

We need a new momentum that focuses on "Building Communities". The American Association of Community and Junior Colleges (AACJC) recently issued a report prepared by the Commission on the Future of Community Colleges which proposes that the theme "Building Communities" become the new rallying point for the community college in America. The Commission, chaired by Dr. Ernest Boyer of the Carnegie Foundation, defines the term "community" not only as a region to be served, but also as a climate to be created. Community Colleges can inspire partnerships based upon shared values and common goals. (I am proud to point out that our own Chancellor for Community Colleges, Dr. Joyce Tsunoda was among the 18 national community college leaders who served on the Futures Commission).

Strengthening our connections beyond the college - with schools, industry, business, social agencies and policy groups - will become a key strategy in the building of community. Through collaboration, we can reaffirm our mandate to respond to the needs of our under-represented groups. Our Colleges, geographically separated by the Pacific Ocean, yet close to the people, can offer a convenient forum for thoughtful discourse; we can serve as a gathering place where persons of various constituencies can meet to explore common problems.

Hawaii's community colleges can provide the connections for our under-represented groups. We share that institutional commitment at Kauai Community College to strengthen our connections beyond the college. The attached chart shows the vision we have of enhancing our cultural heritage through the establishment of a Hawaiian Studies Center where we can provide activities focusing on building an educational community for our Native Hawaiian population. The creation and establishment of a Hawaiian Studies program will enable the College to integrate the efforts of the community and many of our social agencies into a coherent program which enhances our Native Hawaiian culture. Through the establishment of this center, we can begin to offer a wide variety of activities unique to our island setting. Such offerings will include credit and non-credit offerings ranging from Hawaiian music to language and archeology. Workshops such as Interpret Hawaii and customized training focusing on our Hawaiian values will seek to tell the story of our islands. Our services provided through the program will reach out to our community with a host of cultural events. Our faculty and staff will reach out and serve as valuable resources to Punana Leo, a Hawaiian early education program, to the public schools in their Hawaiian Language immersion program, and most importantly to the families they serve in Hawaiian communities scattered throughout the islands.

Let me share with you how the connections established through Kauai Community College enabled the College to make a significant contribution in the lives of a very special group of Native Hawaiians, the people of Niihau. Niihau, sometimes called the Forbidden Island, is located off the coast of Kauai. The people of Niihau are all Native Hawaiians who use the Hawaiian language as their only spoken and written language. Let me tell you the story of three of our recent graduates.

Our first graduate is James, the first male from Niihau who graduated from Kauai Community College. James was recruited into our auto-body repair program by a counselor funded through a grant made possible by the Alu Like Voc Ed Project under the Carl Perkins Act. While in our auto-body program he also enrolled in an Adult Basic Skills program being offered by the Kamehameha Schools through a grant under the Carl Perkins Act. He later transferred into our welding program and graduated with a degree in welding. He came to the College as a welfare recipient and left with basic skills, a marketable vocational skill, and enhanced self esteem. He is currently employed as a welder with one of our sugar plantations. Many agencies provided support throughout his semesters at the College but the most crucial support was given through a caring faculty member who served as a mentor both in and out of the shop.

We are proud of our two women graduates from Niihau who graduated from our early education program. One woman is a single parent with five children. She is currently a bi-lingual teacher working in a public elementary school to implement the Kamehameha Elementary Education Program (KEEP), a model curriculum developed by the Kamehameha Elementary Demonstration School. The other woman is the director of a Hawaiian pre-school called Punana Leo, a family-based education center which receives support from the Education for Native Hawaiians programs.

Kauai Community College and Hawaii's Community Colleges can do more for our under-represented minorities. We can move beyond the early intervention being provided through the parent-education programs. We can move beyond the vocational education offerings provided through the Carl Perkins Act. We can provide powerful partnerships working with elementary and secondary schools. Working in partnership with our colleges and universities, we can be the connection to increase the transfer rates among Native Hawaiian students.

Let me share the story of one of our rare individuals. Ilei Beniamina was born on the island of Niihau. Her native tongue is Hawaiian. Her elementary school years were spent on Niihau. She later left Niihau and graduated from Kamehameha High School. She enrolled at Leeward Community College and then transferred to the University of Hawaii at Hilo where she received her baccalaureate degree in Hawaiian Studies. She is the first person from the island of Niihau to receive a bachelor's degree. Today, she is the first person from Niihau employed by the University of Hawaii serving as a counselor at Kauai Community College. She is an excellent role model for many of our Native Hawaiian students who may have lost the vision that they too can succeed in higher education.

Hawaii's Community Colleges bear a special responsibility to assure that our institutions effectively address the needs of our minority students, in particular, our Native Hawaiian students. We need to actively advocate institutional behavior that will enhance the quality of services provided to Native Hawaiian students and other minorities. Today we are in danger of failing to meet our goals of providing a way out of economic and social disadvantage for our Native Hawaiian students. We need a new momentum. The situation facing our Native Hawaiian students is not unlike the situation described by Dr. Frank Newman, Executive Director of the Education Commission of the States.

In the May 1988 report of the Commission on Minority Participation in Education and American Life, Dr. Newman wrote:

> "We have underestimated the depth and complexity of the situation as well as the need for sustained institutional and governmental commitment. We also have found that some of the more difficult barriers to full participation by minority young people are not so obvious. An unacceptably large number conclude at an early age that education is not for them. Even among those who make it into four year colleges and universities, attrition rates are unacceptably high. This calls for a new understanding and a more creative approach to the barriers to success faced by minority youth from kindergarten to graduate school."

How will the Native Hawaiian compete in this world? How will they be able to penetrate technological barriers? How will they be able to develop into productive citizens of our World? How will they be able to do any of these things if we fail to bring our Native Hawaiian students into the economic mainstream?

Some of the answers to the above questions can be found in a significant longitudinal study called The Kauai Longitudinal Study or The Children of the

Garden Island. In 1955, 698 infants on Kauai became participants in a 30-year study that has shown how individuals triumph over physical disadvantages and deprived childhoods. The study reinforces the need for early-intervention programs such as the parent-education project. The researchers found that all children can be helped to become more resilient if adults in their lives encourage their independence, teach them appropriate communication and self help skills and model as well as reward acts of helpfulness and caring. The life stories of the resilient individuals on the Garden Island taught the researchers that competence, confidence and caring can flourish even under adverse circumstances if young people encounter adults in their lives who provide them with a secure basis for the development of trust, autonomy and initiative. Attached is an article from the Scientific American which summarizes their findings.

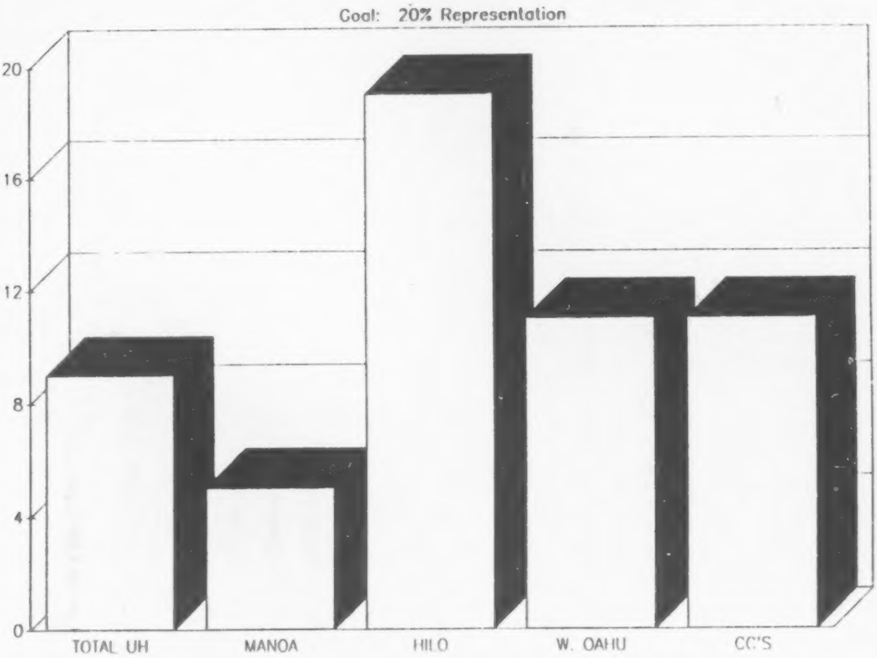
The community college, at its best, can be that center where trust, autonomy and initiative are nurtured in the lives of our Native Hawaiians. It can be a center for problem-solving in adult illiteracy. It can be a center for leadership training. It can bring together agencies to strengthen services to our Native Hawaiians. It can coordinate efforts to provide child care, transportation and financial aid. It can serve as a focal point to improving the quality of life for our Native Hawaiian students. It can be a center where we can raise the expectations of our young people for higher education.

The establishment of Native Hawaiian programs at each of the seven community colleges who serve as the front line institutions serving our Native Hawaiian population will demonstrate the institutional and governmental commitment to improving the numbers of Native Hawaiians pursuing higher education. An appropriation of $500,000 for each of the seven colleges to initiate this new momentum is requested. Hawaii's Community Colleges have a pivotal role in getting Native Hawaiians into the pipeline. Our Colleges have a leadership role to play in turning the tide of minority participation. On each of our campuses, in each of our communities, it will require an arduous process of revising campus agenda, changing individual priorities and habits, willfully disrupting the status quo. With your help at the federal level, we hope that we can transform our colleges into a system that will serve all of our students, especially our under-represented minorities, in the years to come.

UNDER-REPRESENTED HAWAIIAN & FILIPINO IN THE UNIVERSITY OF HAWAII SYSTEM

	1983		1985		1987		1989	
	Hawaiian	Filipino	Hawaiian	Filipino	Hawaiian	Filipino	Hawaiian	Filipino
CC SYSTEM	10.6	15.4	10.5	16.6	10.9	16.4	11.4	17.0
HONOLULU	10.1	15.1	10.7	17.0	10.4	18.2	13.4	19.4
KAPIOLANI	8.1	13.3	8.0	13.9	8.4	12.6	8.7	12.6
KAUAI	10.9	25.5	12.0	27.1	11.6	27.7	13.6	31.7
LEEWARD	10.1	17.6	9.5	19.1	9.5	18.9	9.9	18.9
MAUI	14.5	17.6	14.1	19.0	17.8	19.8	16.2	20.3
WINDWARD	16.7	3.3	16.4	3.2	17.5	2.6	12.5	2.9

Percent Representation of Hawaiians Within Major Component Programs of the University of Hawaii
Fall 1987



Senator INOUYE. I thank you very much, Dr. Iha.

So the record will be complete, the provost mentioned the Island of Niihau several times. The Island of Niihau is one of the northern islands of the island chain. It is a very small island. It is privately owned. And a handful of native Hawaiian families, the owners have not been too open in permitting outsiders to move in and out. As a result the education has been not quite on par with that of the public school system of the State of Hawaii.

And what the community colleges, especially on the Island of Kauai are trying to achieve is to bring about a change in the lifestyle, so that the young men and women of Niihau will be able to reap the benefits of our democracy.

Your chart is not part of the testimony. Somehow I did not receive it. You mentioned that native Hawaiians are underrepresented. What are the numbers there?

Mr. IHA. I think the numbers for the community colleges statewide, we have for fall of 1989, 11 percent of our student enrollment are Hawaiian or part Hawaiian. I think the goal is to have 20 percent representation within our community colleges.

Senator INOUYE. How long will you take to bring this up to 20?

Mr. IHA. I think the chart that I presented showed kind of a plateau in terms of participation of Hawaiians. We had 10.6 percent in 1983 and 1989 was 11.4 percent which shows a very minimal——

Senator INOUYE. You mentioned the Carl Perkins Vocational Education Act, I presume you support that.

Mr. **Iha**. Yes; I do.

Senator **Inouye**. Do you support an increase in the funding?

Mr. **Iha**. Yes; I do.

Senator **Inouye**. The administration, as you know, has frozen the fiscal 1990 for 1991. And so you are in favor of increasing that.

Mr. **Iha**. Yes; I think the case histories that I mentioned showed the impact in terms of the lives of native Hawaiians who were touched by the efforts of councils that were funded through the Carl Perkins Act.

Senator **Inouye**. I thank you very much, sir.

Mr. **Iha**. Thank you.

Senator **Inouye**. The following eight witnesses together with Provost Iha will be discussing matters of unique interest in the State of Hawaii, the problems of native Hawaiians.

STATEMENT OF HON. DANIEL AKAKA, U.S. REPRESENTATIVE FROM HAWAII

Senator **Inouye**. The next witness is a very distinguished Member of the U.S. House of Representatives, a very dear friend of mine. He is the senior Member of the House from Hawaii, the Honorable Daniel Akaka.

Congressman Akaka is a proud member of the native Hawaiian community. His ancestry is one of nobility and royalty.

Congressman.

Mr. **Akaka**. Thank you very much, Senator Inouye and members of the committee.

I really appreciate this opportunity to testify before you in support of programs which enhance the lives of native Americans. I also for the record want to say, Senator, that you have been a great leader for the Hawaiian community and have moved many of the concerns of the Hawaiians forward to a point where the people of Hawaii are beginning to receive some of the benefits. And we are testifying today on two of them.

One is Native Hawaiian Health Care Act and the other is Native Hawaiian Education Act which have opened many doors in an effort to serve the needs of the native Hawaiians.

Low self-esteem, alcohol, and drug dependency, low rates of retention in schools, high risk of disease, and low survival rates all confirm that the native Hawaiian population is engaged in a difficult battle to keep up with the changing society.

With continued funding of the programs contained in the Native Hawaiian Education Act the goal of establishing the importance of education is addressed at the infant and preschool age through the family based education centers. Parents are given the opportunity to participate directly in education of their children. And this is a forward look at education not only in Hawaii but in our country. And as we notice throughout the country there is a movement toward this type of education.

It is at this point that the seed of education is planted to be continually nurtured through the model curriculum and gifted and talented programs.

The opportunity for native Hawaiian children to advance to postsecondary levels of education becomes available through the higher education demonstration program. In addition the needs of native

Hawaiian students who require special educational assistance are addressed through the special education program. All of these programs are instrumental in preparing our younger generations for careers and positions in an increasingly competitive society.

The Native Hawaiian Health Care Act has enabled the associate members of Papa Ola Lokahi to join together in continuing the fight against health risks common in the native Hawaiian population. Poor health among native Hawaiians is a very severe problem.

In a report released by the Hawaii State Department of Health on March 12, 1990, infants of Hawaiian ancestry continue to have the greatest chance of dying before their first birthday compared to all other ethnic groups. For every 1,000 native Hawaiian births more than 10 infants die before age 1. If you were to compare the native Hawaiian population to black, Hispanic and Asian minority populations in the United States, the incidents of native Hawaiians becoming afflicted with diabetes, heart disease, and different forms of cancer is consistently higher. Only through the support of Papa Ola Lokahi can the goal of upgrading native Hawaiian health be achieved.

In closing, Mr. Chairman, the testimony gathered here today will give Members of Congress, Federal and State agencies a clearer understanding of the current obstacles the native Hawaiians face in the areas of education and health. It will also assist us in getting a better understanding of how these deficiencies can be addressed and resolved. And this will be very helpful for Congress people to help make correct decisions.

Again, I thank you, Senator Inouye, for your leadership in organizing these hearings. And I look forward to working with you and the committee on the concerns being raised today. Thank you very much for this opportunity to testify before you.

Senator INOUYE. Congressman, I thank you very much for your testimony.

You have been a very articulate and effective voice for the native Hawaiians, not here, not only in Hawaii but also in the Congress of United States.

Would you care to join me here as we receive testimony from the witnesses?

Mr. AKAKA. I thank you very much for the invitation, Senator. But I am going to have to run back to a meeting, two meetings rather.

Senator INOUYE. Well, I know that you would like to be here if it were not for other pending appointments but thank you again.

Mr. AKAKA. If you do not mind, I will sit here for 15 minutes.

Senator INOUYE. Sure enough. Come right up.

STATEMENT OF SHARON MIYASHIRO, DEPUTY DIRECTOR, HAWAII STATE DEPARTMENT OF LABOR

Senator INOUYE. Our next witness is the deputy director of the Hawaii State Department of Labor, Ms. Sharon Miyashiro. It is always good to see you, Sharon.

Ms. MIYASHIRO. Thank you, Mr. Chairman, for giving me this opportunity to update you and the subcommittee on the State of Hawaii's Jobhelp Store project and our employment service job bank automation system. You should have my written testimony. And what I would like to do this morning is just highlight some of those areas.

Senator INOUYE. I will assure all of you that your prepared statements will be made part of the record in full.

Ms. MIYASHIRO. Thank you.

We are extremely grateful for your support, Senator Inouye. Through your efforts and the assistance of the U.S. Department of Labor the Jobhelp Store was funded in July last year, and we have begun services in two high growth areas and are expanding services throughout the State.

The Jobhelp Store was developed to mutually benefit our immigrants and Pacific islanders who need special help to become employable and our employers who desperately need skilled workers. And, Mr. Chairman, Hawaii continues to experience a severe labor shortage. Our current unemployment rate at 2.9 percent is one of the lowest in the Nation.

We are thus focusing on helping our clients overcome barriers, such as English language fluency, low levels of reading, writing and computational skills, a lack of cultural awareness in every day living know-how in their new homeland, lack of appropriate vocational skills, and the inability to transfer their existing knowledge and skills to meet the demands of the local job market.

We developed the Jobhelp Store as a broad-based project drawing upon all appropriate resources within our department and within the community making full use of the various strengths and services unique to each which when pieced together would offer Jobhelp Store clients the comprehensive services they need.

Let me digress of a moment here to talk about our bilingual immigrant outreach and Jobhelp Store workers who are immigrants themselves. Because they are from similar cultures are our clients, they are especially sensitive and aware of the apprehensions and concerns as well as the attitudes and desires of our clients, these workers bridge the gap between a life constrained by cultural and educational barriers and one that affords opportunities.

We have found that many immigrants unaccustomed to seeking training and jobs need personal one-on-one support and guidance at the point of first contact. Our workers provide that support to humanize the process for them. This caring contact is at the heart of the Jobhelp Store. We want to offer help in a nonbureaucratic culturally sensitive manner that would help immigrants transition more easily into their new lives.

Although we experienced a longer than anticipated startup due to the many administrative and operational matters that had to be resolved, we have open two Jobhelp Stores in high employment growth areas of west Hawaii and west Oahu. But our experience also indicated the need to expand our services earlier that originally planned to all counties, so that presently Jobhelp Store services are available on the islands of Maui and Kauai. And we have increased coverage to all of the Island of Oahu and of Hawaii.

We are at the point where enrollments and activities are accelerating and we fully expect to meet our first year enrollment objective of 700 by June 30. We like to think of the Jobhelp Store in terms of an incubator project that can nurture new growth, new ideas, new services, improve upon traditional services, and deliver meaningful productive results for the clients we serve.

We are testing various approaches to make our services easily accessible, we are placing our stores where people go. We have so far placed two of our Jobhelp Stores in shopping malls. We are open during nontraditional office hours from 7:45 to 6 o'clock at night on weekdays and on Saturday mornings.

We have also found that many immigrants live in outlying areas, and they have difficulty in coming to our office. So we are also looking into a van to provide mobile outreach services. To ensure that our services are appropriate, we are looking into developing special assessment tools better suited for those who lack English fluency. And to tailor training to their needs, we are developing night and weekend classes, flexible entry and exit times, so trainees can attend classes to meet their own schedules, and customized training to meet their specific training needs.

While heavy emphasis is placed on bringing new workers into our labor force, we cannot ignore the underemployed who also need help, but who cannot afford to quit their jobs to attend training classes. And I might add that we have found that many of these immigrants are multiple wage earners and are working at entry level wages. And so we hope to upgrade them, and these are the people that we want to help to upgrade their education and skills even while employed, to improve their chances for better employment and most importantly for long term self-sufficiency in their new homeland.

From our 6-month experience we have found that much more has yet to be done for the estimated 40,000 immigrants and Pacific islanders in our State. We are again seeking your support for funding for program year 1991 to continue, strengthen and broaden our services to this group in such areas as developing immigrant learning centers in selected outlying areas with significant immigrant or Pacific islander populations, establishing speech laboratories to aid immigrants in learning better conversational English which we found to be a major requirement of our employers, developing entrepreneurship training, and developing immigrant youth programs, such as paid internships and orientation and preparation for college and higher education.

Mr. Chairman, there is a lot of work to be done and new ground to break in immigrant employment and training services. And through your help the Jobhelp Store is well on its way to accomplishing this.

Mr. Chairman, I would also like to take this opportunity to inform you of the status of our employment service job bank system. As I testified last year, we were able to begin automating our job bank system, using one time savings from our State and Federal funds. Our automated labor exchange is presently a skeletal system, which conducts job matching only. They are also leasing most of the equipment and operating software, since we lack funds for immediate purchase.

From our operating budget we must divert approximately $500,000 to $600,000 annually for the duration of the lease, whereas a purchase cost is about $300,000. We need additional resources not only for the purchasing of equipment and software for the system to be more cost effective, but also for developing enhancements to expand its effectiveness to better meet the needs of Hawaii's job seekers and employers.

PREPARED STATEMENT

In my written testimony I have included some of the areas where we would like to enhance the system. Mr. Chairman, the two projects that I have mentioned, the Jobhelp Store and our ES employment service automation project will assist Hawaii to meet the challenges of providing long term self-sufficiency for our immigrants and Pacific islanders—a segment of our population facing multiple barriers to employment—for alleviating our labor shortage and the need for skilled workers to compete globally, and improving our employment service automation system to enable us to design our services to be more flexible, comprehensive, efficient, and accessible.

We thank you for your continued support of our efforts to ensure that our services are responsive to the changing needs of Hawaii's diverse population.

Thank you.

[The statement follows:]

STATEMENT OF SHARON Y. MIYASHIRO

THANK YOU, MR. CHAIRMAN, FOR GIVING ME THIS OPPORTUNITY TO UPDATE YOU AND THE SUBCOMMITTEE ON THE DEPARTMENT'S JOBHELP STORE PROJECT AND ON OUR EMPLOYMENT SERVICE AUTOMATION.

THE JOBHELP STORE

THE JOBHELP STORE IS AN EMPLOYMENT AND TRAINING PROJECT TO HELP ASIAN IMMIGRANTS AND PACIFIC ISLANDERS IN HAWAII, ESPECIALLY THOSE NEWLY ARRIVED, TO ACQUIRE THE ENGLISH LANGUAGE FLUENCY, BASIC EDUCATION, SKILL TRAINING, AND SUPPORT SERVICES NEEDED IN ORDER TO SUCCESSFULLY OBTAIN AND RETAIN SUITABLE, AND REWARDING EMPLOYMENT.

WE ARE EXTREMELY GRATEFUL AND PLEASED THAT THROUGH YOUR EFFORTS, THE JOBHELP STORE WAS FUNDED NOT ONLY FOR THE FIRST YEAR OF JULY, 1989 THROUGH JUNE, 1990 TO PROVIDE SERVICES IN TWO HIGH-GROWTH AREAS OF HAWAII BUT ALSO FOR A SECOND YEAR THROUGH JUNE, 1991 TO EXPAND SERVICES THROUGHOUT THE STATE WHERE MANY IMMIGRANTS ALSO RESIDE.

AS YOU MAY KNOW, HAWAII CONTINUES TO EXPERIENCE A SEVERE LABOR SHORTAGE, REQUIRING SOME EMPLOYERS TO SEARCH OUTSIDE OF HAWAII FOR NEEDED WORKERS. CURRENTLY, THE UNEMPLOYMENT RATE AT 2.9% IS ONE OF THE LOWEST IN THE NATION. WE DEVELOPED THE JOBHELP STORE TO MUTUALLY BENEFIT IMMIGRANTS WHO NEED SPECIAL HELP TO BECOME EMPLOYABLE AND EMPLOYERS WHO DESPERATELY NEED THE WORKERS TO RUN THEIR BUSINESSES. WE ARE HELPING IMMIGRANTS TO OVERCOME BARRIERS SUCH AS ENGLISH LANGUAGE FLUENCY; LOW LEVELS OF READING, WRITING, AND COMPUTATIONAL SKILLS; LACK OF CULTURAL AWARENESS AND EVERYDAY LIVING KNOW-HOW; LACK OF

APPROPRIATE VOCATIONAL SKILLS; AND THE INABILITY TO TRANSFER KNOWLEDGES AND SKILLS PREVIOUSLY ACQUIRED IN THEIR HOMELAND TO MEET THE DEMANDS OF THE LOCAL JOB MARKET.

WE DEVELOPED THE JOBHELP STORE AS A BROAD-BASED PROJECT, DRAWING UPON ALL APPROPRIATE RESOURCES WITHIN OUR DEPARTMENT AND IN THE COMMUNITY, MAKING FULL USE OF THE VARIOUS STRENGTHS AND SERVICES UNIQUE TO EACH, WHICH, PIECED TOGETHER, WOULD OFFER JOBHELP STORE CLIENTS THE COMPREHENSIVE SERVICES THEY NEED.

WITHIN OUR DEPARTMENT, WE HAVE COORDINATED SEVERAL OFFICES TO PROVIDE THE CORE SERVICES OF ASSESSMENT, COUNSELING, REFERRAL TO TRAINING AND SUPPORT SERVICES, AND JOB PLACEMENT; PUBLICITY AND OTHER PUBLIC INFORMATION; LABOR MARKET AND CAREER INFORMATION AND GUIDANCE; SERVICES TO IMMIGRANT YOUTHS AT SELECTED HIGH-SCHOOLS; CONTRACTING OF COMMUNITY AGENCIES SERVING IMMIGRANTS TO PROVIDE OUTREACH AND OTHER SERVICES; AND OUR JTPA ADMINISTRATIVE OFFICE TO PROVIDE CONSULTATION, GUIDANCE, AND MONITORING OF THE GRANT ADMINISTRATION.

OUTSIDE OF THE DEPARTMENT, WE WORK WITH IMMIGRANT AND REFUGEE-SERVING COMMUNITY-BASED PROVIDER ORGANIZATIONS TO DO OUR OUTREACH, PROVIDE ACCULTERATION AND ENGLISH LANGUAGE EDUCATION, AND OTHER SERVICES TAILORED FOR THE SPECIFIC NEEDS OF OUR NEWLY ARRIVED IMMIGRANTS USING BI- AND MULTI-LINGUAL WORKERS, MOST OF WHOM ARE IMMIGRANTS THEMSELVES.

LET ME DIGRESS A MOMENT HERE TO TALK ABOUT OUR BI-LINGUAL IMMIGRANT OUTREACH AND JOBHELP STORE WORKERS AND SHARE A COMMON CONCERN THEY HAVE. BECAUSE THEY ARE FROM SIMILAR CULTURES AS OUR JOBHELP STORE CLIENTS, THEY ARE ESPECIALLY SENSITIVE AND

AWARE OF THE APPREHENSIONS AND CONCERNS, AS WELL AS THE ATTITUDES AND DESIRES OF OUR CLIENTS. THESE WORKERS ARE THE FIRST BRIDGE FOR OUR IMMIGRANTS TO SPAN THE GAP BETWEEN A LIFE CONSTRAINED BY CULTURAL AND EDUCATIONAL BARRIERS AND ONE THAT WOULD AFFORD MORE OPPORTUNITIES. THEY HAVE FOUND THAT MANY IMMIGRANTS UNACCUSTOMED TO SEEKING TRAINING AND JOBS NEED PERSONAL ONE-ON-ONE SUPPORT AND GUIDANCE AT THE POINT OF FIRST CONTACT. OUR WORKERS PROVIDE THAT SUPPORT TO "HUMANIZE" THE PROCESS FOR THEM. THIS CARING CONTACT IS AT THE HEART OF OUR JOBHELP STORE. WE WANT TO OFFER HELP IN A NON-BUREAUCRATIC, CULTURALLY-SENSITIVE MANNER THAT WOULD HELP IMMIGRANTS TRANSITION MORE EASILY INTO A NEW LIFE.

IN ADDITION TO WORKING WITH OUR COMMUNITY IMMIGRANTS OUTREACH NETWORK, WE ALSO REFER ELIGIBLE CLIENTS TO OTHER COUNTY AND NON-PROFIT PROGRAMS TO MAXIMIZE THE AVAILABILITY OF JOBHELP STORE RESOURCES; AND WE, OF COURSE, ALSO WORK CLOSELY WITH VARIOUS PUBLIC AND PRIVATE TRAINING PROVIDERS, ENROLLING IMMIGRANTS IN CLASSES RANGING FROM BASIC EDUCATION TO COMPUTER TECHNOLOGY AND BEYOND. ALL THESE ACTIVITIES ARE COORDINATED THROUGH CASE MANAGERS WHO WORK CLOSELY WITH THE CLIENT AND APPROPRIATE PROVIDERS TO CONTRIBUTE TO PLAN FOR AND ENSURE THAT NEEDED SERVICES ARE PROVIDED.

ALTHOUGH WE EXPERIENCED A LONGER THAN ANTICIPATED START-UP DUE TO THE MANY ADMINISTRATIVE AND OPERATIONAL MATTERS THAT HAD TO BE RESOLVED, TWO JOBHELP STORES HAVE BEEN OPENED IN THE HIGH EMPLOYMENT GROWTH AREAS OF WEST HAWAII AND WEST OAHU. SUBSEQUENTLY, WE SAW THE NEED TO EXPAND THE SCOPE OF OUR SERVICES EARLIER THAN PLANNED TO ALL ISLANDS IN HAWAII. PRESENTLY, JOBHELP STORE SERVICES ARE NOW AVAILABLE ON THE ISLANDS OF MAUI AND KAUAI AND WE HAVE INCREASED COVERAGE TO ALL

OF THE ISLAND OF OAHU AND THE ISLAND OF HAWAII. WE ARE AT THE POINT WHERE ENROLLMENTS AND ACTIVITIES ARE ACCELERATING AND WE FULLY EXPECT TO MEET OUR FIRST YEAR ENROLLMENT OBJECTIVE OF 700 BY JUNE 30, 1990. WE ARE ENROLLING ABOUT 100 PERSONS A MONTH, WITH A THIRD OF THE PARTICIPANTS BEING ENROLLED IN SOME TYPE OF TRAINING; AND WE EXPECT THAT NUMBER TO GROW AS THEIR PRELIMINARY SERVICES ARE COMPLETED.

THE JOBHELP STORE IS A DEMONSTRATION PROJECT. WE LIKE TO THINK OF IT IN TERMS OF AN "INCUBATOR PROJECT". A PROJECT THAT CAN NURTURE NEW GROWTH, NEW IDEAS, NEW SERVICES; IMPROVE TRADITIONAL SERVICES; AND DELIVER MEANINGFUL, PRODUCTIVE RESULTS FOR THE CLIENTS WE SERVE.

TO BE EASILY ACCESSIBLE, A STORE MUST BE LOCATED IN PLACES WHERE PEOPLE GO AND MUST BE OPEN AT CONVENIENT TIMES. WE HAVE SO FAR PLACED TWO OF OUR JOBHELP STORES IN SHOPPING MALLS AND ARE OPEN DURING NON-TRADITIONAL OFFICE HOURS, UNTIL 6:00 PM ON WEEKDAYS AND A HALF-DAY ON SATURDAYS. WE HAVE FOUND THAT MANY IMMIGRANTS LIVE IN POCKETS IN OUTLYING AREAS AND MAY HAVE DIFFICULTY IN COMING TO THE OFFICE. THUS WE ARE LOOKING INTO USING A VAN TO PROVIDE FOR MOBILE OUTREACH SERVICES TO THESE PEOPLE. WE ARE ALSO DEVELOPING NIGHT AND WEEKEND TRAINING CLASSES; TAILORING TRAINING TO THE SPECIFIC NEEDS OF IMMIGRANTS; DEVELOPING FLEXIBLE ENTRY AND EXIT TIMES SO TRAINEES DO NOT HAVE TO WAIT UNTIL THE NEXT CLASS STARTS; AND LOOKING INTO DEVELOPING SPECIAL ASSESSMENT TOOLS BETTER SUITED FOR THOSE WHO LACK ENGLISH FLUENCY.

WE ARE PLANNING TO DEVELOP JOB ENRICHMENT AND UPGRADE TRAINING PROGRAMS FOR WORKERS FOR THOSE EMPLOYERS WHO CURRENTLY HAVE ON STAFF IMMIGRANT WORKERS. THIS EFFORT WILL NOT ONLY

HELP RETAIN WORKERS BUT ALSO ALLEVIATE WORKER SHORTAGES AT HIGHER SKILL LEVELS. WHILE HEAVY EMPHASIS IS PLACED ON BRINGING NEW WORKERS INTO OUR LABOR FORCE, WE CANNOT IGNORE THE UNDEREMPLOYED WHO ALSO NEED HELP BUT WHO CANNOT AFFORD TO QUIT THEIR JOBS TO ATTEND TRAINING CLASSES. ALTHOUGH WE DON'T HAVE SPECIFIC DATA ON THE NUMBER OF MULTIPLE WAGE-EARNER IMMIGRANTS, WE DO KNOW THAT MANY IMMIGRANTS WORK IN LOWER SKILL JOBS -- OFTEN IN MORE THAN ONE -- IN ORDER TO SUPPORT THEIR FAMILIES. THE JOBHELP STORE WANTS TO OFFER THESE PEOPLE A CHANCE TO UPGRADE THEIR EDUCATION AND SKILLS, EVEN WHILE EMPLOYED, TO IMPROVE THEIR CHANCES FOR BETTER EMPLOYMENT, AND, MOST IMPORTANTLY, FOR LONG-TERM SELF SUFFICIENCY IN THEIR NEW HOMELAND.

IN THIS REGARD, WE ARE LINKING WITH OUR DEPARTMENT'S STATE-FUNDED HIGH GROWTH INDUSTRY TRAINING FUND. FOR EXAMPLE, ONE FOCUS HAS BEEN ON THE HEALTHCARE INDUSTRY WHICH HAS BEEN GROWING RAPIDLY AND FACING WORKFORCE SHORTAGES. WE ARE LOOKING INTO HOW WE MIGHT DEVELOP OUR IMMIGRANT WORKER POTENTIAL TO MEET THIS AND OTHER HIGH-GROWTH INDUSTRY WORKER NEEDS. WE ARE ALSO DEVELOPING LINKAGES WITH OUR STATE APPRENTICESHIP PROGRAMS AS WELL AS PLANS FOR VOLUNTARY RELOCATION AND JOB PLACEMENT OF REFUGEES FROM ONE ISLAND TO ANOTHER TO RELIEVE CERTAIN WORKER SHORTAGES IN ACUTE AREAS.

AS WE IMPLEMENT THE JOBHELP STORE PROJECT, IT BECOMES CLEAR TO US THAT THE JOBHELP STORE IS DEFINITELY MEETING A NEED. BUT MORE IMPORTANTLY, WE SEE THE JOBHELP STORE AS BEING A CATALYST FOR PULLING TOGETHER AND SYNTHESIZING THE VARIOUS RESOURCES IN OUR STATE WHICH SPECIALIZE IN IMMIGRANT SERVICES WITH OTHER EMPLOYMENT RESOURCES IN A HIGHLY VISIBLE, ACCESSIBLE, EFFICIENT, AND COMPREHENSIVE MANNER.

WE ARE FORTUNATE TO HAVE BEEN PROVIDED THE FUNDS TO START THIS PROJECT, AND FROM OUR SIX MONTH EXPERIENCE, WE HAVE FOUND THAT MUCH MORE HAS YET TO BE DONE FOR THE ESTIMATED 40,000 IMMIGRANTS AND PACIFIC ISLANDERS IN OUR STATE. WE ARE AGAIN SEEKING YOUR SUPPORT FOR FUNDING FOR PY91 IN THE AMOUNT OF $2.4 MILLION TO CONTINUE, STRENGHTEN, AND BROADEN OUR SERVICES TO THIS GROUP.

WE INTEND TO CONTINUE AND IMPROVE THE ACTIVITIES THAT PROVE SUCCESSFUL IN OUR FIRST AND SECOND YEARS, AND TO FOCUS ON NEW INITIATIVES SHOULD THE THIRD YEAR FUNDING BECOME AVAILABLE, AS FOLLOWS:

1) DEVELOPING IMMIGRANT LEARNING CENTERS IN SELECTED AREAS, POSSIBLY CO-LOCATED WITH CHILD CARE FACILITIES, ESPECIALLY IN OUTLYING AREAS WITH SIGNIFICANT IMMIGRANT OR PACIFIC ISLANDER POPULATIONS, TO PROVIDE MORE ACCESSIBLE AND COORDINATED SERVICES.

2) ESTABLISHING SPEECH LABORATORIES TO AID IMMIGRANTS IN A SELF-DIRECTED EXPERIENCE OF LEARNING BETTER CONVERSATIONAL ENGLISH. WE HAVE FOUND THAT THIS IS A MAJOR REQUIREMENT OF EMPLOYERS AND WE BELIEVE THAT A MORE EFFECTIVE APPROACH BEYOND CLASSROOM TRAINING MUST BE DEVELOPED.

3) DEVELOPING ENTREPRENEURSHIP TRAINING WITH LINKAGES TO THE DEPARTMENT OF BUSINESS AND ECONOMIC DEVELOPMENT, SMALL BUSINESS ASSOCIATION, AND OTHER INTERESTED ORGANIZATIONS.

4) DEVELOPING IMMIGRANT YOUTH PROGRAMS, BOTH DURING SCHOOL AND SUMMERS, SUCH AS PAID INTERNSHIPS WITH EMPLOYERS COMBINED WITH EDUCATION AND WEEKLY GROUP SEMINARS COVERING PERSONAL

AND EMPLOYMENT GUIDANCE AND INTERNSHIP FEEDBACK DISCUSSIONS; ALSO, DEVELOPING COLLEGE AND OTHER HIGHER EDUCATIONAL ORIENTATION AND PREPARATION SUCH AS ATTENDANCE AT ON-SITE SCHOOL LECTURES AND WORKSHOPS, DOING ACTUAL SCHOOL ASSIGNMENTS, AND THE LIKE.

THESE ARE SOME IDEAS THAT WE HAVE DISCUSSED AS WE CONTINUE TO WORK IN THIS PROJECT. DURING THE NEXT YEAR WE ARE CERTAIN THAT OTHER IDEAS ON HOW TO MORE EFFECTIVELY ASSIST IMMIGRANTS TO SELF-SUFFICIENCY WILL EMERGE. OUR JOBHELP STORE ADVISORY COMMITTEE, COMPRISED OF REPRESENTATIVES FROM COMMUNITY GROUPS AS WELL AS PRIVATE INDIVIDUALS, WILL CONTINUE TO ASSIST US IN OUR PLANNING AND DEVELOPMENT.

MR. CHAIRMAN, THERE IS A LOT OF WORK TO BE DONE AND NEW GROUND TO BREAK IN IMMIGRANT SERVICES. THE JOBHELP STORE IS ON ITS WAY TO ACCOMPLISH THIS AND WE SEEK YOUR CONTINUED SUPPORT OF OUR EFFORTS.

EMPLOYMENT SERVICE AUTOMATION

I WOULD ALSO LIKE TO TAKE THIS OPPORTUNITY TO INFORM YOU OF THE STATUS OF OUR EMPLOYMENT SERVICE AUTOMATION.

AS I TESTIFIED LAST YEAR, WE HAVE BEEN ABLE TO BEGIN OUR AUTOMATION USING ONE-TIME SAVINGS FROM OUR STATE AND FEDERAL FUNDS. THE SYSTEM, CALLED "ALEX" - AUTOMATED LABOR EXCHANGE -- IS AT PRESENT A SKELETAL SYSTEM WHICH CONDUCTS JOBMATCHING ONLY. WE ARE ALSO LEASING MOST OF THE EQUIPMENT AND OPERATING SOFTWARE WHICH IS COSTLY BUT NECESSARY AS FUNDS ARE NOT AVAILABLE FOR IMMEDIATE PURCHASE. THIS LEASING CONCERNS US AS

FUNDS MUST BE DIVERTED ANNUALLY FROM OUR OPERATING BUDGET FOR STAFF AND OTHER NECESSARY COSTS. OVER THE REMAINING TERM OF THE LEASE, WE ESTIMATE A LEASE PAY-OUT OF $500,000 - $600,000 COMPARED TO A PURCHASE COST OF ABOUT $300,000.

WE NEED ADDITIONAL RESOURCES NOT ONLY FOR PURCHASING EQUIPMENT AND SOFTWARE TO MAKE THE SYSTEM MORE COST EFFECTIVE BUT ALSO TO DEVELOP ENHANCEMENTS TO EXPAND ITS EFFECTIVENESS. WE ARE FAR FROM THE SYSTEM ENVISIONED IN THE OMNIBUS TRADE AND COMPETITIVENESS ACT OF 1988 (SEE SECTION 6307 OF PL 100-418).

TO BETTER MEET THE NEEDS OF JOBSEEKERS AND EMPLOYERS IN HAWAII, WE WOULD LIKE TO DEVELOP THE FOLLOWING ENHANCEMENTS, AMONG OTHERS:

1) INTERFACE OUR SYSTEM WITH THAT OF OUR UNEMPLOYMENT INSURANCE SYSTEM TO EXPEDITE WORK REGISTRATION, CLAIMANT FOLLOW-UP, AND SHARING OF JOB PLACEMENT-RELATED INFORMATION.

2) ESTABLISH A CHILD CARE RESOURCE DATA BANK TO HELP US RECRUIT AND REFER SOME OF THE 28,000 PARENTS WHO COULD WORK IF THEY HAD ACCESS TO CHILD CARE.

3) SET UP REMOTE STATIONS IN HIGH-TRAFFIC LOCATIONS USING TOUCHSCREEN TV TECHNOLOGY OR OTHER EASY-TO-USE TECHNOLOGY WITH A "TALKING PHONE BOOK" - TYPE CONCEPT TO PROVIDE THE PUBLIC INFORMATION, ON EMPLOYMENT AND TRAINING SERVICES, JOBSEEKING TIPS, JOB AND LABOR MARKET INFORMATION, AND SO ON, TO RECRUIT WORKERS AND FACILITATE LISTING OF JOBS BY EMPLOYERS. CURRENTLY THE GOVERNOR'S SUBCABINET TASK FORCE ON HUMAN SERVICES/RESOURCES COMPRISED OF THE STATE DEPARTMENTS OF HUMAN SERVICES, HEALTH AND LABOR ARE

PILOTING A TOUCHSCREEN VIDEO ON OUR SERVICES. THESE WORKSTATIONS ARE BEING PLACED ON A ROTATION BASES IN TWELVE COMMUNITY SITES TO TEST WHETHER THE PUBLIC WILL FIND THEM EASY ENOUGH TO USE TO GET APPROPRIATE SERVICES. THESE MACHINES HAVE BEEN PROGRAMMED IN ENGLISH, SAMOAN, AND ILOCANO. SHOULD THIS SYSTEM PROVE SUCCESSFUL, WE COULD BUILD ON IT TO PROVIDE DIRECT INITIAL REGISTRATION OF JOBSEEKERS AND LISTING OF JOBS BY EMPLOYERS AT REMOTE SITES THROUGHOUT THE STATE.

4) DEVELOP EASY-TO-USE, VISUALLY STIMULATING, INTERACTIVE PROGRAMS FOR JOBSEEKERS TO USE FOR SELF-ASSESSMENT, CAREER AND TRAINING GUIDANCE, AND JOBSEEKING SKILLS.

5) DEVELOP LINKAGES WITH OTHER SOCIAL PROGRAMS TO MINIMIZE DUPLICATE RECORD ENTRIES AND DATA BASES AND PROMOTE CLOSER CASE MANAGEMENT SERVICES.

TO IMPLEMENT THESE ENHANCEMENTS FOR A MORE EFFICIENT AND EFFECTIVE SYSTEM WILL REQUIRE AN ESTIMATED $1.0 MILLION OVER THE NEXT TWO YEARS.

CONCLUSION

THESE EMPLOYMENT PROJECTS WILL ASSIST HAWAII TO MEET TWO OF THE MANY CHALLENGES FACING US: ALLEVIATING OUR LABOR SHORTAGE AS WELL AS PROVIDING LONG TERM SELF-SUFFICIENCY FOR OUR IMMIGRANTS AND PACIFIC ISLANDERS -- A SEGMENT OF OUR POPULATION FACING MULTIPLE BARRIERS TO EMPLOYMENT; AND IMPROVING OUR AUTOMATION SYSTEM TO MAKE OUR SERVICES MORE FLEXIBLE, MORE COMPREHENSIVE, MORE EFFICIENT, AND MORE ACCESSIBLE. WE THANK YOU FOR YOUR CONTINUED SUPPORT OF OUR EFFORTS IN ENSURING THAT OUR SERVICES ARE RESPONSIVE TO THE CHANGING NEEDS OF HAWAII'S DIVERSE POPULATION.

Senator **Inouye**. I thank you very much. And I wish to commend the State of Hawaii for taking the initiative and coming forth with such an innovative program.

For the record it should be noted that most of the clients or beneficiaries of this immigrant assistance program are immigrants who have come to this land as a result of actions taken by the U.S. Government. They are primarily from Vietnam, Laos, and Cambodia. And they come into a strange place with very few friends, if any. And this outreach program that Hawaii has inaugurated, has been done with great sensitivity and success.

And I note that other areas in our Nation are now looking at your program to very likely adopt the same format. So I congratulate you.

Ms. **Miyashiro**. I thank you, Senator.

Senator **Inouye**. Thank you very much.

STATEMENT OF HON. ENI FALEOMAVAEGA, U.S. REPRESENTATIVE FROM AMERICAN SAMOA

Senator **Inouye**. Our next witness—I was just told that we have with us a very distinguished Member of the U.S. House of Representatives. He is the delegate from American Samoa, one of our territories in the Pacific, the Honorable Eni Hanken Faleomavaega. Is that not an exotic name? Faleomavaega.

Congressman, pleasure to have you with us.

Mr. **Faleomavaega**. Thank you, Mr. Chairman.

Mr. Chairman, and members of the subcommittee, I appreciate this opportunity to testify before the committee relative to the number of concerns of the American-Samoan people residing both in the United States and American Samoa.

I would like to begin my remarks before the committee by discussing the Job Training Partnership Act which addresses the needs of native Samoan-Americans who reside in the States of Hawaii, California, and Washington.

Through your leadership, Mr. Chairman, the Federal Government, for the first time in fiscal year 1989, appropriated Federal funds to provide job training in related assistance programs for native Samoan-Americans residing in California and in the State of Hawaii. And I want to personally thank you for this initiative.

In 1990 the funding was increased to $2.5 million to provide: $1.5 million for the Job Hope, the Hawaii Jobhelp Store for immigrants and refugees. Mr. Chairman, historically the native Samoan-Americans have not been properly accounted for in the census. The best estimate is that over 100,000 Samoans are residing in the United States with the majority of them residing in Hawaii, California, and the State of Washington.

As you may be aware, Mr. Chairman, according to the 1980 census, the national per capita of native Samoan-Americans was $3,570. Per capital income of native Samoans living in Hawaii at that time was about $2,700, which was far less than any ethnic group surveyed.

Without a doubt low income and high unemployment rates are closely related. It is quite simple, Mr. Chairman. A significant percentage of Samoan families throughout the United States live on welfare and in poverty. Mr. Chairman, in 1985 with the assistance of Mrs. Pat Luce the executive director of the National Office of Samoan Affairs in California, outlined before the subcommittee an employment opportunity, some very critical statistics data concerning the plight of native Samoan-Americans who live in the United States.

And let me just share with you some of the 1980 census data; 27.5 percent of native Samoan-Americans lived at poverty level as opposed to 9.6 percent of the total U.S. population; 37.5 percent of native Samoan-Americans who live in Hawaii, lived at poverty level as opposed to the 7.8 percent of the total State population; 21 percent of native Samoan-Americans in California lived at poverty level as opposed to 8.7 percent of the total State population; 10.2 percent of the native Samoan-Americans residing in Hawaii are unemployed, which is twice the State rate.

Although the State unemployment rate in Hawaii is low, Samoans are still disproportionately represented in the unemployment statistics. It is common knowledge that native Samoan-American work at the most menial jobs available.

Mr. Chairman, of all the minority groups in the United States, I believe the native Samoan-Americans suffer the most economically. Indeed these problems are due primarily to educational, cultural, and language barriers. These barriers can be overcome through targeted education and training programs such as those provided under the Job Training Partnership Act program.

Ms. Kiliali Alailima the director of the Samoan Providers Association, I believe, may have already discussed the accomplishments of the Hawaii program which has been in operation for just over 1 year. The California office reports that a total of 231 persons have been served through the past 8 months of operation with 84 job placements. It gives me a great sense of pride to report that these two offices have placed many unemployed native Samoan-Americans in positions not subsidized by public funds, and are dedicated to elevating native American Samoans from being welfare recipients to productive members of their respective communities.

Mr. Chairman, I would like to reinforce one area of weakness in the JTPA program which has been brought to my attention both by Ms. Alailima and Ms. Luce, which is the assumption that qualified staff are available in both program offices. This is simply not the case. They are not seeking additional funding for staff development, but would like to be able to utilize a small portion of training funds for this purpose.

Mr. Chairman, there are currently several legislative initiatives moving through the Congress which you and I and Congressman Akaka have been very instrumental in moving, hopefully to provide for the needs the people of American Samoa.

One specifically is the inclusion of American-Samoan Guam under the gifted and talented program and, Mr. Chairman, which you initiated under the legislation of Senate bill 2082. And as you have invited me to introduce the bill in the House version along with Congressman Ben Blaz, and Congressman Daniel Akaka.

This legislation, if enacted, will grant opportunities to gifted and talented elementary and secondary school students in the territories of American-Samoan Guam with special programs in education and also address the culture and historical backgrounds of these students. It will be a means to the realization and development of their potential. As gifted individuals they embody a valuable untapped resource, which without these programs, may go undiscovered.

And I wish to express my personal thanks to you, Mr. Chairman, for your initiative in this important effort on behalf of the young people in Samoa and in Guam.

Mr. Chairman, last month I introduced H.R. 3981 which proposes to amend the Social Security Act to include the American Samoa under the supplemental security income program. There are approximately 1,600 poverty level aged and disabled individuals living alone in Samoa without resources which are available to other Americans who reside in other parts of the United States. Those programs available to their brothers and sisters in Puerto Rico, Guam, and the Virgin Islands and other Pacific territories, are not available to the elderly in American Samoa.

The aged, the blind and disabled men and women I seek to help with this legislation have been caught between two systems. When Social Security went into effect in American Samoa, this group of people were too old to contribute long enough to qualify for minimum benefits. The territorial retirement system did not begin until 1971. By that time many of these people have already left the work force or had so little income or time remaining that they were also included from benefits under this system.

The elderly and severely handicapped individuals, some 1,600 of them, have nowhere to turn without resources or Federal support programs. American Samoa currently does not receive aid for dependent children or food stamp benefits, and it is not seeking these programs.

I do believe however, Mr. Chairman, that SSI benefits should be extended to relieve the more critical needs of our severely handicapped and elderly who do not qualify for any other assistance.

Another area of special concern to me in other Pacific territories is the vocational education reauthorization legislation. The House passed H.R. 7 in May of last year without substantive changes in the territorial program. The Senate, however, in the Senate bill S. 1109, has recommended deleting America Samoa and other Pacific jurisdictions from the basic program funding formula and is recommending a far different delivery and administrative plan.

The plan structure proposes to put a private organization known as the Center for the Advancement of Pacific Education, colloquially referred to as CAPE, as the agency between the U.S. Department of Education and the territorial governments. This means, in essence, that all funds for vocational education for the Pacific territories will be granted to CAPE, which in turn would subgrant to the territorial governments.

DOD Secretary Carvaso is on record as being opposed to what he terms as an administrative arrangement which is unprecedented in our experience. This legislation if implemented, Mr. Chairman, as proposed in S. 1109, will place CAPE between the territorial governments and the U.S. Department of Education for the receipt of funding and administration of vocational educational programs.

I see this arrangement as being detrimental to the vocational education program as presently administered in Samoa, and I do not support CAPE as an administrative agency of the Department of Education.

If enacted, it will impact American Samoa in two specific areas. To employ health professionals and bilingual individuals to provide health promotion and disease prevention services, focusing on specific health problems such as maternal and child health, nutrition, mental health illness, and adolescent violence in the State of Hawaii, with plans for extending these services to Samoans living in the United States.

And two, to establish the Pacific basin health council to coordinate health programs and expenditures for the Pacific island territories.

I will be working closely with your office, Mr. Chairman, and Congressman Louis Stokes and the House Subcommittee on Health Environment as the House version H.R. 3240 proceeds in the House.

Mr. Chairman, this ends my testimony and again I want to express my personal gratitude and appreciation to you and members of the committee; especially to your efforts for taking so many initiatives that are needful in the area of education and job program opportunities for Samoans living in the United States and especially in the State of Hawaii.

Senator INOUYE. Thank you very much, Congressman.

I want to commend you for the extraordinary leadership you have provided to the Samoan community. And in recognition of this, I am pleased to advise the group here that last year Samoa conferred upon the Congressman the title of chief. So we have with us a chief from Samoa. Chief Faleomavaega.

Chief Mavaega, if you wish to join us here, please do so. The statistics that you cited obviously are horrendous and almost unbelievable. But they were statistics that came forth from the 1980 census, and I am certain the 1990 census will show that the work that you have done will have resulted in better statistics. I am certain of that, sir.

Mr. FALEOMAVAEGA. Mr. Chairman, I appreciate the invitation, and I would like to submit my written statement to be made part of the record.

Senator INOUYE. Without objection it is so ordered.

Mr. FALEOMAVAEGA. Since I have just summarized it basically. Thank you very much, Mr. Chairman.

Mr. AKAKA. Mr. Chairman, I thank you for this opportunity of saying a word about my colleague in the House. Congressman Faleomavaega has made a difference in the House with his friendship with other Members of the House as well as with his work with American Samoa.

I have seen him and have been told that he has been very effective in the committees and his work in helping the people of Samoa. Having been on House staffs in the past, the Congressman of Samoa has been able to use his skill and abilities to persuade other members to help him with his quest in helping the people of Samoa.

He has offered bills, and some of them have been passed already. And as a new Member, relatively new Member of the House of

Representatives, I want to tell you that he has done a great job for the people of Samoa. Thank you very much.

Senator **Inouye**. Thank you. I had the good fortune of visiting Samoa after almost 30 years of absence. And I was accompanied by Chief Faleomavaega. I also wish to commend you, and I am certain that people of Samoa join me in this, for the leadership you have provided and the assistance program following the recent devastating Typhoon Ofa.

As a result of your leadership the support activities have been expeditiously carried out. I wish to relate to you the commendation that I heard from the Department of Defense and the liaison services you and your offices provided them. And I wish to commend you.

Thank you very much.

Mr. **Faleomavaega**. Mr. Chairman, thank you very much and certainly appreciate the kind words, and especially from the gentleman, my distinguished colleague from the House. Congressman Akaka has always been a sense of strength for me over the years, both formally as a staff counsel to the House Interior Committee. But now as I sit along side with him, I have always depended on his wisdom and his guidance in leading me through the mirrored maze that is so common.

And many people to not realize what it means to be working along with 439 other Members of Congress and try to memorize 440 faces, Mr. Chairman, is quite a job, let alone in trying to remember the 100 distinguished Senators that make up this side of the body. But I certainly appreciate those kind words.

Thank you very much.

Mr. **Akaka**. Mr. Chairman, I should add that often we have been accused on the floor of the House, whenever I talk to the Congressman from Samoa, they ask me whether we are having a Polynesian caucus. [Laughter.]

Senator **Inouye**. It takes two to caucus. [Laughter.]

STATEMENT OF KILALI ALAILIMA, EXECUTIVE DIRECTOR, SAMOAN SUPPORT PROVIDERS

Senator **Inouye**. Our next witness is the executive director of the Samoan Support Providers. A lovely and talented Ms. Kilali Alailima.

It is good to see you again, Kilali.

Ms. **Alailima**. Hon. Senator Inouye and members of the Senate Subcommittee on Labor, Health, Related Agencies and Appropriations, thank you for this opportunity to testify. And I would also like to thank you, Senator Inouye. You have been an unparalleled, a leader among leaders in your support of minority concerns and issues. And we especially have been very grateful for your support of the Samoan concerns and issues in the United States. Thank you very much.

I am Kilali Alailima, executive director of the Samoan Service Providers Association, a nonprofit Samoan organization that has advocated for the needs of Hawaii Samoans for more than 5 years and manages the Samoan Job Training and Partnership Act program for the State of Hawaii.

I will not go into the statistics that have already been cited by Congressman Faleomavaega. I would only like to add that we also in addition, have a very high youth gang population. Our youth represent more than one-half of the Hawaii Samoan population. We are very concerned about what is happening with youth.

On behalf of our organization I am pleased to give you an update on our program today. As you know, we opened our offices in January 1989 and hired 10 staff to manage two programs. Our largest program is the training and employment programs, which receive a total of $454,000 annually from the Federal Government to provide counseling, job training, and job placement services.

In 1989, we enrolled and served 300 participants. Of this number we placed 62 adults in jobs, 53 youths in a summer youth employment and training program, cosponsored with Kapiolani Community College. We have also placed 70 participants in occupational skills training, 32 in basic skills training, 8 in work experience, and 9 in on the job training. To help overcome barriers to employment we also provide support services that include child care work tools, work clothing, transportation, and medical services.

Training placements have been at both public and private accredited institutions for occupational skills training that includes computer operator, clerical nursing, electronics, construction, travel industry, welding, et cetera. Training institutions include the State community colleges and private training institutions.

We have assisted people in finding jobs as drivers, medical assistants, cooks, sales clerks, managers, porters, carpenters, roofers, painters, and secretaries. Our knowledge of the training and employment opportunities in this State is expanding as we become better linked with the community at large.

Our second program, the Samoan outreach and liaison, started in July 1989 and its purpose is to provide outreach and advocacy services to Samoans other than in the field of employment. It is staffed by a coordinator and a media specialist. To date it has served a total of 103 people in the area of crisis intervention, housing, interpretation and translation, immigration matters, activities for youth at risk, name changes, community organizing, and community building.

On September 30, 1989, this program coordinated the first Samoan family life conference at Kaumakapili Church for more than 100 members of the Samoan community, including 17 gang members from the Halawa housing project. In October, 40 counselors and other State officials attended a cultural sensitivity workshop sponsored by SSPA and the Pacific Business Center.

Other organizational activities included a very successful Samoan career day at the University of Hawaii, cosponsored by SSPA and attended by over 100 Samoan high school youth. Another such activity is being planned for April 1990.

During the first months of 1989 SSPA served as a facilitator in meetings between McKinely Carwash management and their 50 Samoan employees. These meetings helped to clarify cross-cultural misunderstandings, work-related concerns, employee benefits, employee concerns, and created a more positive and supportive work environment.

SSPA also played a key role in helping the Hawaii Samoan community organize a relief effort to ship supplies to Western and American Samoa after Hurricane Ofa devastated the islands of Western and American Samoa.

We have had a very challenging and exciting year, and we have learned much about what is involved in establishing an agency to address the needs of our community. We are very grateful for all the support given to us by the State, State agencies that include the Hawaii State Department of Labor and Industrial Relations, the Department of Health and Human Services, the community colleges, State and city officials, elected local leaders, congressional representatives, and especially to you, Senator Inouye from Hawaii and your hard working staff.

In helping the Hawaii Samoan community progress toward greater self-sufficiency, the Samoan Service Providers Association will need to continue to build on the foundation that it has established through its employment and training program. Part of that building has been the training of our bilingual staff who are excellent bridgemakers, but do not necessarily have the full range of skills and expertise to provide counseling geared to training and employment.

The JTPA program presumes a trained staff in place and therefore does not provide the funds for staff training except through the administrative portion of the JTPA budget, which is limited to 20 percent and restricts our training activities.

Our Samoan counterparts in California, the National Office of Samoan Affairs, also shares the same concern. Therefore, I would like to request of this committee that an allowance be made to enable the Samoan JTPA programs to provide training for their staff with funds that are available under training. This action would allow us to fully develop the potential of our staff and represents a long term investment which we believe would make for better programs.

Besides occupational skills training and job preparation, our organization has also been aware through its school outreach program that there is a great need for educational support for Samoans seeking higher education and professional careers. Relatively few Samoans enter college compared to the population at large, and the retention rate for this population is very low.

In discussions with youth from low-income areas, such as the public housing projects, money, limited exposure, the need to work to support the family, and the inability to pass the university entrance examinations, have been some of the reasons given for not continuing to college. To reverse this trend the Samoan Service Providers is helping to make strong linkages between Samoan students in the high schools and the university in order to create a support environment for students seeking higher education.

Senator Inouye, and most esteemed members of this subcommittee, it is very important that these efforts to address the needs of the Samoan population in Hawaii and other parts of the United States, including the National Office of Samoan Affairs in California, continue.

I am here today to communicate to you that funds you have provided us with are fueling programs which are making a difference in our respective communities. Its managers and staff are dedicated to making these programs successful.

PREPARED STATEMENT

In closing, we ask that you please support funding for Samoans in the United States. We are seeking a total of $2.5 million in JTPA funds for all three States, California, Hawaii, and Washington. The Samoan Service Providers Association would also like to request that $1 million be set aside for educational funds to assist Samoans—youth in particular—in gaining access to higher levels of education eventually leading to professional careers. Fa'afetai tele lava. Thank you.

[The statement follows:]

STATEMENT OF MS. KILALI ALAILIMA

INTRODUCTION

Senator Inouye and members of the Senate Subcommittee on Labor, Health and Related Agencies under Appropriations. Thank you for this opportunity to testify today.

I am Kilali Alailima, Executive Director of the Samoan Service Providers Association [SSPA], a nonprofit Samoan community-based organization that has advocated for the needs of Hawaii Samoans for more than 5 years and manages the Samoan JTPA Training and Employment Program [STEP] for the State of Hawaii.

STATUS OF THE SAMOAN JOB TRAINING PROGRAM

On behalf of our organization, I am pleased to give you an update on our program to date. As you know, we opened our office in January 1989 and hired 10 staff to manage two programs. Our largest program is the training and employment program which receives a total of 454,000 annually from the Federal Government to provide counseling, job training and job placement services.

In 1989, we enrolled and served 300 participants. Of this number, we placed 62 adults in jobs, and 53 youth in a Summer Youth Employment and Training Program cosponsored with the Kapiolani Community College. We also have placed 70 participants in occupational skills training, 32 in basic skills training, 8 in work experience, and 9 in on-the-job training. To help overcome barriers to employment we also provide support services that include child care, work tools, work clothing, transportation, and medical services.

Training placements have been at both public and private accredited institutions for occupational skills training that include computer operator, clerical, nursing, electronics, construction, travel industry, welding, etc. Training institutions include the State community colleges and private training institutions.

We have assisted people in finding jobs as drivers, medical assistants, cooks, sales clerks, managers, porters, carpenters, roofers, painters, and secretaries. Our knowledge of the training and employment opportunities in this state is expanding as we become better linked with the community at large.

Our second program, the Samoan Outreach and Liaison, started up in July 1989 and its purpose is to provide outreach and advocacy services to Samoans other than employment. It is staffed by a coordinator and a media specialist. To date it has served a total of 103 people in the area of crisis intervention, housing, interpretation and translation, immigration matters, activities for youth at risk, name changes, community organizing and community building.

On September 30, 1989, this program coordinated the first Samoan Family Life Conference at Kaumakapili Church for more than 100 members of the Samoan community, including 17 gang members from the Halawa Housing Project. In October, 40 counselors and other state officials attended a cultural sensitivity workshop sponsored by SSPA and the Pacific Business Center.

Other organizational activities included a very successful Samoan Career Day at the University of Hawaii cosponsored by SSPA and attended by over 100 Samoan high school youth. Another such activity is being planned for April 1990. During the first 8 months of 1989 SSPA served as facilitator in meetings between the McKinley Carwash management and their 50 Samoan employees. These meetings helped to clarify cross-cultural misunderstandings, work-related concerns, employee benefits, employee concerns and create a more positive and supportive work environment. SSPA also played a key role in helping the Hawaii Samoan community organize a relief effort to ship supplies to Western and American Samoa after Hurricane Ofa devastated the islands of Western and American Samoa.

We have had a very challenging and exciting year and we have learned much about what is involved in establishing an agency to address the needs of our community. We are very grateful for all the support given to us by the State, State agencies that include the Hawaii State Department of Labor and Industrial Relations, the Department of Health and Human Services, the community colleges, State and city officials, elected local leaders, congressional representatives, and especially the Senior Senator from Hawaii and his hardworking staff.

To make lasting change in the Samoan community, the Samoan Service Providers Association needs to continue to build on the foundation it has established, which is its employment and training program through the Job Training and Partnership Act [JTPA]. This program provides for occupational skills training to adults looking for immediate employment. However, there is also a great need and a demand for educational support for Samoans, especially our youth, seeking professional careers. Relatively few Samoans enter college compared to the population at large.

In discussions with youth from low income areas such as the public housing projects, money, limited exposure, need to work to support the family, and the inability to pass the University entrance examinations have been some of the reasons given for not continuing to college. To reverse this trend, the Samoan Service Providers Association is actively making a link between students from Hawaii public high schools and the Samoan university students to create a climate of support for students seeking higher education.

Senator Inouye and most esteemed members of this subcommittee, it is very important that these efforts to address the needs of the Samoan population in Hawaii and other parts of the United States, including the National Office of Samoan Affairs in California, continue. I am here today to communicate to you that funds you have provided us with are fueling programs which are making a difference in our respective communities. Its managers and staff are dedicated to making these programs successful.

In closing, we ask that you please support funding for Samoans in the United States. We are seeking a total of $2.5 million in JTPA funds for all three states, California, Hawaii and Washington. The Samoan Service Providers Association would also like to request that $1 million be set aside for educational funds to assist Samoans, youth in particular, in gaining access to higher levels of education eventually leading to professional careers. Fa'afetai tele lava. Thank you.

Senator INOUYE. I thank you very much, Ms. Alailima.

As you know, last year we appropriated $2.5 million for California, Washington, and Hawaii for special job training programs. But this year the administration somehow overlooked that and did not come forth with a recommendation that we repeat the program. However, I can assure you that at the minimum that sum will be reinstated.

We hope we can increase it by another $1 million and make it $3.5 million. I am certain I can find a few dollars in my defense account. So we will make that possible.

Do you project that in the next fiscal year your client load will be greater than that you have testified to?

Ms. ALAILIMA. I am definitely sure it will be. We hope to increase it to about 400. This year has been a year of setting up the program. And it has been a very challenging year. This is new grounds for the Samoan community. It is a very unique program. And there is nothing that has been done like this before.

This year has been a time of developing it, so that it can be tailored to the Samoan community in Hawaii. Next year, I think we will be set to start to increase the numbers and to do much more aggressive and active outreach in the Samoan community.

Senator INOUYE. I thank you.

Mr. **Faleomavaega**. Mr. Chairman, I certainly would like to commend Ms. Alailima for the outstanding work that she has done as the director of the Samoan providers community program for the State of Hawaii.

Mr. Chairman, one thing that is quite unique and the fact that Samoan community is probably less than 1 percent of the total State population. And yet it is apparent that when something happens in the media, it seems that there is 0.5 million Samoans living in the State of Hawaii giving it a very negative stereotype and impact in saying that Samoans are the biggest troublemakers.

And in relation to the fact that there may be Samoan gangs, again, the media plays it in such a way that it seems that they are the only gangs existing in the State of Hawaii, when in fact, that is not true.

And I certainly would like to say that maybe—to the administration—if we provide this kind of funding, which is less than $1 million and to make these young people to be more constructive by way of employment and educational opportunities, think of the losses that could happen in terms of the crimes that they commit.

And I think I have always liked to say that becoming more constructive is a lot better than becoming destructive to the society, and it certainly does not help. And if we put them in prison, it is even more expensive.

So I just hope that the administration will be a little more considerate and understanding that these programs are not a waste, and they are definitely identifiable problems in some segment of our society. And I hope that we will be able to receive the funding, not only for the Samoan communities, but other communities that have a need for this area.

Thank you.

Senator **Inouye**. I thank you very much, Chief. And I thank you, Ms. Alailima.

STATEMENT OF MYRON B. THOMPSON, SENIOR TRUSTEE, KAMEHAMEHA SCHOOLS/BISHOP ESTATE

Senator **Inouye**. Our next witness is a very distinguished member of the Hawaiian community. He is the senior trustee of Kamehameha Schools/Bishop Estate, the Honorable Myron B. Thompson.

Always good to see you, Pinky.

Mr. **Thompson**. Nice to see you, Senator.

Good morning and Chief Faleomavaega, cousin from the South Pacific, it is nice to see you also. Other members of the committee aloha.

My name is Myron Thompson. I am trustee of the Kamehameha Schools/Bishop Estate. First of all, I want to thank you for your continued support of native Hawaiian programs. Together we are making progress and improving the overall well-being of our people.

I would like to make it very clear this morning that the U.S. Department of Education does not fund programs, does not fund programs for the Kamehameha Schools. All congressional funds are for public programs and communities throughout the State of Hawaii.

Along with other agencies, we assist in administering these programs. Beneficiaries include those young people not enrolled in Kamehameha Schools, expecting mothers, parents of infants and toddlers, preschool children, those at risk to drugs, alienated youth in public schools, and those who wind up struggling in higher education.

The educational profile of the native Hawaiian continues to be disheartening. Kindergartners score at the 12 percentile nationally on the Peabody Picture Vocabulary Test. Sixth grade reading achievement is at the 26 percentile. The native Hawaiian dropout rate in the community colleges is 63 percent. The national average is 47.8 percent. While native Hawaiians represent 20 percent of Hawaii's population, they constitute only 9 percent of the enrollment at the University of Hawaii system. Very few make it to graduation.

Native Hawaiians continue to be the most at risk to substance abuse in our State. However, there is good news to report. In place now is a system which provides educational programs to a full range of Hawaiians. From before birth and continuing into the adulthood.

A key goal is to have these services centrally located within the respective communities. We have started with programs administered by the Kamehameha Schools and are working with the Hawaii State Department of Health, the community colleges, and other native providers toward these goals.

Progress is being made in these areas. And children who attended our preschool score at entrance to the public schools kindergartens as many as 17 percentile points higher on a national test compared to Hawaiian students who did not; 11 experimental and control preschool classrooms now participate in a project which studies ways of countering the educational effects of hearing loss.

This is a significant problem in Hawaiian children and native populations across the Nation. We believe this project which you supported to have a national application. Results will be available in 1991.

Library services help many. More than 3,800 students receive regular homework assistance, more than 400 learned about parent-child reading activities. In addition literacy assistance was provided to human services intake centers. Students in the native Hawaiian vocational education program had a lower dropout rate than those in other community college programs.

Our foremost goal is to bring native Hawaiians to parity with their peers in the State and the Nation. In our plans for the future, our highest priority is continued support for family-based educational centers. I might add here that it was your assistance, Senator, with former Senator Weicker of Connecticut that got this program going.

Demographics show that if we are to serve a representative sample of population, we must expand services in early education beginning with funds appropriated last year, we are expanding services in existing centers on Hawaii, Maui, Oahu, and Kauaii. As funds permit, we will have had new centers on Molokai, Hawaii, and Kauaii. This will enable services to more than 1,100 new participants and bring the total served to nearly 2,500.

Your appropriation for fiscal year 1990 was $2.8 million to expand our programs; an increase of $700,000 is needed; thus $3.5 million is our request. In higher education Kamehameha Schools assist nearly 200 Kamehameha School graduates and over 1,000 non-Kamehameha graduates yearly. Your funds will provide annual aid and support to an additional 495 non-Kamehameha graduates in college.

When we first began funding for higher education, only 4 percent of the enrollment at the University of Hawaii were Hawaiian. Today the figure is 9 percent and to reach parity which is 20 percent, your funds are needed; $2 million is requested.

For health professions education $1.8 million is being requested. This will allow the start of a program to aid and provide support services to those persuing health and health-related professions.

And finally, we urge an increase to $1 million for the model curriculum demonstration project. In addition, continued funding of drug education, libraries, vocational education, gifted and talented, and special education.

Mr. Chairman, thank you for this opportunity. In closing, I want to again emphasize that your funds go to the public programs and not to Kamehameha students. Our grant applications are competitive and side evaluations by your staff and others have been positive.

Again, thank you for your attention and your leadership in improving the well-being of all native peoples.

[The statement follows:]

STATEMENT OF MYRON B. THOMPSON

Good morning Mr. Chairman and committee members. My name is Myron Thompson, trustee of the Kamehameha Schools/Bernice Pauahi Bishop Estate.

Thank you for your support of native Hawaiian programs. We appreciate your commitment to native Hawaiians. Together we strive to assist this indigenous group in regaining the stature they had prior to the destruction of their way of life and their nation.

I begin by clarifying, for the record, a misconception held by some. The U.S. Department of Education does NOT fund programs for our private school - The Kamehameha Schools. Congressional funds provide public programs in communities throughout the state of Hawaii that we and other agencies operate in cooperation with the U.S. Department of Education; for young people not accepted into the Kamehameha Schools, for parents of infants and toddlers, preschoolers, for those at-risk to drugs, for those who are struggling in higher education, for those performing poorly in public schools.

Let me now review data on the native Hawaiian population, report progress on present programs, and share future plans.

Some key data on native Hawaiians are:

* Kindergartners score at the 12th percentile nationally on the Peabody Picture Vocabulary Test (PPVT).

* Sixth grade reading achievement is at the 26th percentile.

* The native Hawaiian dropout rate in the community colleges, where vocational education is dominant, is 63% compared to the national average of 47.8%.

* Native Hawaiians are 9% of the enrollees at the University of Hawaii system although they represent 20% of the population. A group of first time native Hawaiian freshmen at the UH Manoa were tracked for 7 years. Only slightly more than a fourth of them actually graduated.

* Native Hawaiians continue to be the most at-risk to substance abuse in our state.

We have, however, made progress. In place now, is a system which provides educational programs to a full range of Hawaiians. Called The Kamehameha System, it is comprehensive - reaching those from before birth into adulthood. One of the concepts of the system is to locate as many services as possible within a community near each other. We start with programs we administer. Parent-infant home visiting programs are housed with traveling and center-based preschool operations. By plan, they are located near or at public elementary schools which use the model reading and language arts curriculum, KEEP. Also in the same communities are a potpourri of programs funded by our organization, you, and others, including tutoring programs in public intermediate schools, Talent Search programs, and alternative programs for public high school drop-outs.

Beyond our own programs and those funded through the U.S. Department of Education, we are collaborating with the Hawaii State Department of Health, the community colleges, and other native providers to encourage central location of native Hawaiian services. Thus, health promotion and disease prevention, social services, employment assistance, elder care, and other services will eventually be at or near the same centers.

Our common goal is to have native Hawaiians be at least at parity with their peers nationwide and in Hawaii.

We are pleased to report:

* Children attending our preschools continue to test significantly higher on the Peabody Picture Vocabulary Test.

* The project you support which studies ways of counteracting the educational effects of hearing loss, significant in Hawaiian children as well as with native populations nationwide, is in 11 experimental and control preschool classrooms. We believe the results can have national applications.

* The evaluation project for the KEEP model curriculum, presently in 8 public schools throughout the state, has begun. We note a particular component, the home-book reading effort, is enthusiastically received by families.

* Recent surveys on substance abuse showed for the first time that young people on the leeward coast, where Drug-Free Schools & Communities monies were spent, are not the most at-risk to substance abuse.

* Library Services supported many. 3,854 students received regular homework assistance; 423 learned about parent-child reading activities; literacy assistance to those not at a functional level was provided at human services intake centers.

* Although still high, students in the Native Hawaiian Vocational Education Program had a lower drop out rate than those in other community college programs.

* Higher education planning is intense. A comprehensive interagency plan, using our money, your money, community money, and encompassing Talent Search, vocational education, college and graduate activities has been developed. Our goal is to have the next generation of native Hawaiian adults educated as well as their peers nationally.

Now let me address the future.

Our highest priority is continued support for Family Based Education Centers. Even our higher education plan recognizes the need to begin early. Demographics indicate that, if we are to serve a representative sample of the population, expansion is required in early education. We intend to start immediately with funds appropriated last year. We will expand services, as funds permit, in existing centers on Hawaii, Maui, Oahu, and Kauai, and add new centers on Molokai, Hawaii, and Kauai. Over 1,100 new participants would be served. Many remain to be served. Current and planned programs will serve 2,475. Data show that there are about 10,000 native Hawaiian children between the ages of 0-5 who live in high need neighborhoods. All are not at-risk, however, and we are determining how many more we must serve. Continued funding is required to maintain the increased operations and expand to meet the remaining community need on every island. We request funding of $3.5 million.

Next is higher education. Our own budget funds nearly 200 Kamehameha Schools graduates and over 1,000 non-Kamehameha graduates yearly. Your funds will provide annual aid and support to an additional 495 non-Kamehameha graduates in college. Needed is $2 million. In health professions education, funds of $1.8 million are requested to start the program and begin aid and support services to those pursuing health and health related fields.

Finally, we urge an increase to $1 million for Model Curriculum Demonstration and continued funding of drug education, libraries, vocational education, gifted and talented and special education.

Mr. Chairman, thank you for this opportunity. I reiterate our concern to set the record straight. Your funds go for public programs, not to Kamehameha Schools students. Our record for administration is good .. we have competitive grant applications and positive site evaluations by your staff and others equally critical and highly revered. We can and do effectively plan and administer public programs.

Should we falter, we expect you to write us off. You would not hesitate...we would expect no different. We intensely share your commitment and obligation to native Hawaiians. By working together now, we look for significant change within one generation and to a time when your dollars are no longer needed.

Thank you.

OUTREACH PROGRAM

Senator INOUYE. I want to thank you very much, Mr. Thompson. Your emphasis on the fact that none of these funds accrue to the benefit of the Bishop Estate Kamehameha Schools is very important. Because there seems to be a misunderstanding in the Hawaii community that what you are providing is the much-needed leadership, providing innovations to assist Hawaiians in education and health. And I wish to commend you for the personal leadership you have shown and the corporate leadership that Kamehameha School has provided in this outreach program for native Hawaiians.

The people here may be interested to know that a few years ago, we provided hearing tests for young Hawaiian children between the ages of 4 and 5, and to our shock and dismay we found that about 70 percent were suffering from measurable hearing loss.

It demonstrated once again that there is a correlation in poor health and poverty. And as a result Gallaudet the world renowned higher education facility for the deaf has opened an operation in the State of Hawaii to assist our teachers in recognizing and teaching these unfortunate young people. We hope that this trend will change. And I am certain that under your guidance we will bring about a massive and dramatic change; 70 percent is obscene.

And I thank you once again, Mr. Thompson. And I can give you this one assurance that knowing that the funds that you have managed over the years have more than amply resulted in good results, we will do our utmost to make certain that these funds are once again appropriated.

Mr. THOMPSON. Thank you, Senator.

Mr. FALEOMAVAEGA. Mr. Chairman, having spent almost one-half of my life in Hawaii, I have always admired and respected Mr. Thompson over the years as a pioneer and especially in areas of trying to bring about a better situation for the native Hawaiian communities and certainly thank him and appreciate his presence here in Washington.

A couple of years ago Mr. Thompson was the chairman and president of the Polynesian Voyaging Society and for which I was very grateful at the invitation of serving as a member of the crew of the famous Hokolea, a double-hull Polynesian canoe that sailed from Hawaii and throughout the various Polynesian islands.

And again, Mr. Thompson has been a pioneer trying to bring our island people together. But more importantly—and I think this has always been a known fact—native Hawaiians have always been at the lowest economic, social ladder in the State of Hawaii in anything that they have tried to do and appreciate your help in giving them this kind of assistance for the needs of the native Hawaiian Americans.

Thank you.

Mr. THOMPSON. Thank you.

Senator INOUYE. I thank you for your mentioning Hokolea. In 2 years this Nation will celebrate the 500th anniversary of the voyage of Columbus. It is a great event, but yet we all know that long before Columbus sailed the Atlantic Ocean a hearty group of Polynesians traveled a longer distance on outrigger canoes.

And recently this heroic voyage was repeated, and it was done under a navigator, a young navigator called Ninoa Thompson. Is Ninoa here?

Mr. THOMPSON. I am sorry, Senator, he is busy trying to put together a budget for another project. So he could not be here today.

Senator INOUYE. Ninoa is Mr. Thompson's son, and he supervised in the building of this canoe which was as close as possible a reproduction of the original. And it sailed these miles which almost doubled the voyage of Columbus. It did not receive the recognition of this Nation, but navigators throughout this world look upon the voyage of the Polynesians as a feat much greater than that of Columbus. And we in Hawaii honor the Hawaiians.

Thank you very much.

Mr. FALEOMAVAEGA. I might also add, Mr. Chairman, that Ninoa Thompson is the first Polynesian navigator that we have had in 400 years.

And for the record, Mr. Chairman, the Polynesians did not drift in rafts as Mr. Heyerdahl has supposedly thought previously. We did sail on canoes, and we knew where we were going. I thank you for your attention to this very important matter as far as the island people are concerned.

Thank you.

Mr. THOMPSON. Congressman, Ninoa sent his best to both of you. Thank you.

STATEMENT OF THOMAS KAULUKUKUI, SR., CHAIRMAN, OFFICE OF HAWAIIAN AFFAIRS

ACCOMPANIED BY:

MASARU OSHIRO, PRESIDENT AND CHIEF EXECUTIVE OFFICER, ALU LIKE

RICHARD PAGLINAWAN, ADMINISTRATOR, OFFICE OF HAWAIIAN AFFAIRS

Senator INOUYE. And now may I call upon a special panel to discuss the economic development in Hawaii. First the chairman of the Office of Hawaiian Affairs, the Honorable Thomas Kaulukukui, Sr., and the president and chief executive officer of Alu Like, Mr. Masaru Oshiro, and the administrator of the Office of Hawaiian Affairs, Mr. Richard Paglinawan. It is always good to see all of you.

Mr. Kaulukukui, would you like to proceed.

Mr. KAULUKUKUI. Aloha, Mr. Chairman and members of the committee. I am Thomas Kaulukukui, Sr., chairman of the board of trustees of the Office of Hawaiian Affairs, and it is my great pleasure to be here today representing the board of trustees and the native people of Hawaii, the Hawaiians.

Let me take about a moment to thank you for all of the help you have given to Hawaiians particularly on problems of health and education. Your support has begun to take effect as shown by Hawaiian agencies working together to address their beneficiaries in common and in the provision of services to minimize and eventually eliminate the problems.

I appeared before you last year and in my testimony gave you a capsule account of this unique organization that I have been privileged to serve since its inception in 1980. Background material on OHA and a status report on some of our activities has been submitted to you under separate cover.

It has been a momentous year since I last testified before the committee. And I will provide you with highlights of OHA's busy and productive time.

To elaborate in 1982, OHA submitted a report entitled "Reparations and Restitution" to the Native Hawaiian Study Commission which set our four principles to bring native Hawaiians into the modern era of Federal native American relations. One, acknowledgement by the United States of the wrongful taking of Hawaiian land; two, provisions of self-government of native Hawaiians; three, provision of a land base for native Hawaiians; and four, monetary compensation.

Then in 1984, OHA pointed out that no final plan for the reparations in achievable until reviewed by the Hawaiian community. To that end we have begun a detailed and extensive consultation process with the community. We believe that Hawaiians are intelligent, aware, and capable of making decisions on issues of importance and have the ability to develop their own concepts.

OHA's role is to be the conduit, the facilitator for this development and repository of the concepts. Toward this end, OHA has developed a long-range plan called iluna aye, moving upward. In July we kicked off what we called Operation Ohana, or the Hawaiian enrollment program. The goal of Operation Ohana is to encourage all Hawaiians to join together beginning with families and expanding to include the entire community and culture. To accomplish this, we have organized an enrollment program which builds on the traditional family system and seeks to give all Hawaiians an opportunity to convert family decisions into action, which keep the community moving upward.

OHA wants to enroll 150,000 Hawaiians as a means to provide the first true demographic information on our people giving us a data base by Hawaiians for Hawaiian use. A second component of iluna aye was Operation Ka Po'e designed to let the Hawaiian community define its own membership through a referendum. Conducted in November 1989 it is a critical exercise in self-determination. Unfortunately due to more immediate political considerations the results of the referendum are on hold until a more opportune time.

Operation EA a third component of iluna aye encompasses a blueprint for native Hawaiian entitlement to correct breaches of trust responsibility toward the Hawaiian community by the Federal Government.

Hawaiians believe that the problems that they face today are rooted in the loss of our land and self-governmental authority. The blueprint is a draft document proposing possible approaches to those issues offering a process to address them. After adequate community review and discussion, the draft will be finalized for presentation to the State and Federal Government for action and will be a true expression of the Hawaiian people.

As the chair of the Office of Hawaiian Affairs, I also chair a legislatively funded task force called Operation Hui Imi to inventory and coordinate the planning of services to Hawaiians. This 15-member group includes representation from agencies and organizations that serve Hawaiians as well as the State legislature and the Congress.

Phase 1 of two reports to the legislature has been completed and a task force will begin the more difficult second phase due in January 1991. Operation Malama Mau is a legislatively funded task force to study ways for the State to better respond to the discovery of important historical sites in Hawaii.

This blue ribbon committee of experts in history, anthropology, historic preservation law, cultural practices, and native rights has already submitted that interim report to the legislature with another to follow in 1991.

One final note, Mr. Chairman. An important issue for Hawaiians relates to the department of Hawaiian homelands. And some of the significant changes proposed to take place there. OHA and DHHL serve the same beneficiary group and we have a good working relationship to coordinate legislative and congressional efforts toward that end.

PREPARED STATEMENT

This concludes the testimony on Hawaiian issues facing OHA that I was asked to present. May I thank you again for your past support and urge its continuance in the future. I can assure you it will be an investment with positive rewards.

Thank you very much.

[The statement follows:]

STATEMENT OF THOMAS KAAUWAI KAULUKUKUI, SR.

ALOHA, MR. CHAIRMAN AND MEMBERS OF THE COMMITTEE. I AM THOMAS KAAUWAI KAULUKUKUI, SR., CHAIRMAN OF THE BOARD OF TRUSTEES OF THE OFFICE OF HAWAIIAN AFFAIRS (OHA), AND IT IS MY GREAT PLEASURE TO BE HERE TODAY REPRESENTING THE BOARD OF TRUSTEES AND THE NATIVE PEOPLE OF HAWAII, THE HAWAIIANS.

LET ME TAKE BUT A MOMENT TO THANK YOU FOR ALL OF THE HELP YOU HAVE GIVEN TO HAWAIIANS, PARTICULARLY ON PROBLEMS OF HEALTH AND EDUCATION. YOUR SUPPORT HAS BEGUN TO TAKE EFFECT AS SHOWN BY HAWAIIAN AGENCIES WORKING TOGETHER TO ADDRESS THE NEEDS OF THEIR BENEFICIARIES-IN-COMMON, AND IN THE PROVISION OF SERVICES TO MINIMIZE, AND EVENTUALLY ELIMINATE, THE PROBLEMS.

I APPEARED BEFORE YOU LAST YEAR, AND IN MY TESTIMONY GAVE YOU A CAPSULE ACCOUNT OF THIS UNIQUE ORGANIZATION THAT I HAVE BEEN PRIVILEGED TO SERVE SINCE ITS INCEPTION IN 1980. THE BACKGROUND MATERIAL ON OHA, AND A STATUS REPORT ON SOME OF OUR ACTIVITIES, HAVE BEEN SUBMITTED AS RESEARCH MATERIAL.

THE MATURATION PROCESS CONTINUES FOR OHA, AND I AM PROUD TO BE THE CHAIRMAN OF THE BOARD AT THIS VERY AUSPICIOUS POINT IN TIME.

LET ME ELABORATE. OHA HAS INITIATED A SERIES OF ACTIVITIES THAT ARE DESIGNED TO MAKE CHANGE - SOME MAJOR, SOME MINOR - ON BEHALF OF ITS BENEFICIARIES. AT THE SAME TIME, OTHER FORCES ARE AT WORK - ON A CONGRESSIONAL LEVEL, AT THE HAWAII LEGISLATIVE LEVEL, AND AT THE COMMUNITY LEVEL. INTERESTINGLY ENOUGH, AS THESE CHANGES BEGIN TO TAKE PLACE, IT CREATES A GREAT DISCOMFORT WITH THOSE WHO HAVE FORGOTTEN HOW TO TRUST. OR PERHAPS NEVER LEARNED, AS HAPPENS WITH OPPRESSED PEOPLES.

RIGHT NOW, MR. CHAIRMAN, HAWAIIANS ARE IN A STATE OF FERMENTATION AND THINGS ARE BUBBLING. WHERE QUESTIONS WERE NEVER BEFORE ASKED, THEY ARE NOW BEING OPENLY DEBATED. WHERE QUIET ACCEPTANCE AND COMPLACENCY WERE ONCE THE RULE, THERE IS NOW INVOLVEMENT AND PARTICIPATION. PERSONALLY, I BELIEVE THIS IS A HEALTHY SIGN OF PEOPLE FEELING EMPOWERED ENOUGH TO START TAKING CHARGE OF THEIR OWN FUTURE.

THE YEAR 1989 WAS MEMORABLE FOR OHA. IN JULY, WE KICKED OFF WHAT WE CALL OPERATION OHANA, OR THE HAWAIIAN ENROLLMENT PROGRAM. THE APPLICATION FORM IS SIMPLE AND BASICALLY A FAMILY GENEALOGY FOR PERSONS EIGHTEEN OR MORE WHO HAVE THEIR OWN HOUSEHOLDS. THE RESPONSE HAS BEEN OVERWHELMING, AND WE ARE FINDING

MORE HAWAIIANS IN THE OTHER 49 STATES AND OTHER PARTS OF THE WORLD THAN WE EVER DREAMED. OHA HAS REGISTRARS IN MOST OF THE WESTERN STATES WHO HAVE BEEN TRAINED TO FILL OUT THE FORMS AND SEND THEM BACK TO BE COMPUTERIZED AND CROSS INDEXED. THE DAY WILL COME, MR. CHAIRMAN, WHEN WE WILL HAVE THE DATABASE TO TELL YOU EXACTLY HOW MANY HAWAIIANS ARE LIVING IN ALMOST ANY AREA OF THE U.S., THEIR AGES, EDUCATION LEVEL AND OTHER SIMPLE INFORMATION. OPERATION OHANA IS AN IMPORTANT ONGOING PROJECT FOR OHA.

IN AUGUST, SENATOR INOUYE CAME HOME AND TOOK THE SENATE INDIAN AFFAIRS COMMITTEE TO EVERY MAJOR ISLAND TO ASK HARD QUESTIONS AND LISTEN PATIENTLY FOR HOURS ON END AS HAWAIIANS WHO NEVER DARED SPEAK PUBLICLY SHARED THEIR FRUSTRATIONS, OBSERVATIONS AND GRATITUDE OVER THE HAWAIIAN HOMES PROGRAM. FOR AN ENTIRE WEEK, THE GOOD SENATOR SAT THROUGH TEARS OF RAGE AND JOY, IN AN UNPRECEDENTED EXPRESSION OF DEMOCRACY AT WORK, ADDRESSING SEVENTY YEARS OF NEGLECT AND INDIFFERENCE.

THE SENATOR HAS FOLLOWED THROUGH ON HIS COMMITMENT TO TRY AND RIGHT THE WRONGS BY CONTINUING TO HAVE MEETINGS WITH COMMUNITY GROUPS ASKING FOR THEIR INPUT AS HE PREPARES AMENDMENTS TO THE COMPLICATED TRUST RELATIONSHIP BETWEEN HAWAIIANS, THE STATE OF HAWAII AND THE FEDERAL GOVERNMENT. THE CLARIFICATION IS NEEDED BUT THERE IS OPPOSITION AT HEARINGS IN THE STATE LEGISLATURE.

ON SEPTEMBER 2, QUEEN LILIUOKALANI'S BIRTHDAY, THE OHA BOARD OF TRUSTEES UNVEILED OPERATION EA, A BLUEPRINT FOR NATIVE HAWAIIAN ENTITLEMENTS FROM THE FEDERAL GOVERNMENT. THE BLUEPRINT IS A DRAFT DOCUMENT THAT BEGINS A COURSE OF ACTION TO CORRECT BREACHES OF TRUST BY THE FEDERAL GOVERNMENT THAT STARTED YEARS AGO AND CONTINUE TODAY. ULTIMATELY, AFTER THE HAWAIIAN COMMUNITY HAS TAKEN THE OPPORTUNITY TO EXPRESS ITS CONCERNS AND RECOMMENDATIONS, THE BLUEPRINT WILL REQUIRE CONGRESSIONAL AND PRESIDENTIAL ACTION.

AS A DECLARATION OF COMMITMENT, OHA TRUSTEES, STAFF AND OVER TWENTY VOLUNTEERS WENT THROUGHOUT THE STATE IN A SERIES OF INFORMATIONAL COMMUNITY MEETINGS TO EXPLAIN THE BLUEPRINT, ASK PEOPLE TO READ IT AND PROVIDE TESTIMONY AT HEARINGS ON THE BLUEPRINT TO BE HELD AT A LATER DATE. SIMULTANEOUSLY, AN OHA TEAM MADE TEN PRESENTATIONS IN FOURTEEN DAYS IN SIX MAINLAND CITIES WITH LARGE HAWAIIAN POPULATIONS.

THE BLUEPRINT WAS ALSO MAILED TO 64,000 HAWAIIANS ON THE OHA VOTER REGISTRATION LIST, AND THOUSANDS MORE DISTRIBUTED. AFTER SIX WEEKS, HEARINGS

WERE HELD IN OCTOBER, WHERE VERBAL AND WRITTEN TESTIMONY WERE RECEIVED. IN RESPONSE TO THE OVERWHELMING REQUEST FOR MORE TIME, THE TRUSTEES EXTENDED THE DEADLINE FOR A YEAR, INCORPORATING IDEAS AND SUGGESTIONS IN A SECOND DRAFT WHICH WILL SOON BE READY FOR CIRCULATION.

OHA HAS ALSO BEEN ENGAGED IN OPERATION KA PO'E, AN INITIATIVE FUNDED BY THE STATE LEGISLATURE TO CONDUCT A COMPREHENSIVE REFERENDUM OF THE HAWAIIAN PEOPLE TO DETERMINE THEIR WISHES REGARDING A SINGLE DEFINITION OF HAWAIIAN. RIGHT NOW, THE QUALIFICATION TO RECEIVE BENEFITS FROM THE OHA AND HAWAIIAN HOMES TRUSTS REQUIRES 50% OR MORE HAWAIIAN BLOOD, A DEFINITION THAT DIVIDES FAMILIES AT THEIR VERY CORE. THE TRUSTEES ARE COMMITTED TO TRY AND CHANGE THE DEFINITION AS IT PERTAINS TO OHA, WHICH WILL ALLOW A MORE EQUITABLE DISTRIBUTION OF BENEFITS.

REFERENDUM RESULTS WERE OVERWHELMINGLY IN FAVOR OF CHANGING THE DEFINITION TO MAKE ALL HAWAIIANS ELIGIBLE FOR BENEFITS FROM OHA. UNFORTUNATELY, DUE TO OTHER POLITICAL CONSIDERATIONS, THE RESULTS OF THE REFERENDUM WILL BE PLACED ON HOLD FOR A MORE OPPORTUNE TIME.

AS THE CHAIR OF OHA, I ALSO CHAIR A LEGISLATIVELY FUNDED TASK FORCE, OPERATION HUI IMI, TO INVENTORY AND COORDINATE THE PLANNING OF SERVICES TO HAWAIIANS. THIS 15-MEMBER GROUP INCLUDES REPRESENTATION FROM AGENCIES AND ORGANIZATIONS SERVING HAWAIIANS.

PHASE ONE OF TWO REPORTS TO THE LEGISLATURE HAS ALREADY BEEN COMPLETED, AND THE TASK FORCE IS REGROUPING TO BEGIN THE MORE DIFFICULT SECOND PHASE, DUE IN JANUARY 1991.

THE STATE LEGISLATURE PROVIDED OHA WITH FUNDS TO COORDINATE, STAFF AND ADMINISTER A TASK FORCE ON HISTORIC PRESERVATION, OPERATION MALAMA MAU. THE TASK FORCE INCLUDED PERSONS WITH EXPERTISE IN HAWAIIAN CULTURAL PRACTICES, ANTHROPOLOGY, LANGUAGE, HISTORIC PRESERVATION LAW, NATIVE RIGHTS AND LAND USE. THE TASK FORCE WAS CHARGED WITH IDENTIFYING THE PROBLEMS, STATUTORY AND PRACTICAL, THAT IMPEDE EFFORTS TO PRESERVE SITES OF CULTURAL, RELIGIOUS OR HISTORIC VALUE TO HAWAIIANS.

AN INTERIM REPORT HAS BEEN SUBMITTED TO THE LEGISLATURE, AND THE TASK FORCE IS NEXT COMMITTED TO SUBMIT A LEGISLATIVE PACKAGE RECOMMENDING CHANGES IN STATE LAW TO BETTER PROTECT HAWAIIAN SITES. IT WILL ALSO CLARIFY THE MAJOR ROLE THAT HAWAIIAN CULTURE AND HAWAIIAN PEOPLE MUST ASSERT AND ASSUME IN LAW

IF THE PROTECTION EFFORT IS TO SUCCEED. A FINAL REPORT IS DUE TO THE LEGISLATURE IN JANUARY 1991.

ONE OF THE FIRST PROJECTS TO BE FUNDED BY OHA WAS THE NATIVE HAWAIIAN LAND TITLE PROJECT, STILL DOING QUIET TITLE LAWSUITS TO SETTLE THE INTERESTS OF HAWAIIANS RELATIVE TO A PARCEL OF REAL PROPERTY. THIS PROJECT IS ADMINISTERED BY THE NATIVE HAWAIIAN LEGAL CORPORATION (NHLC), A NON-PROFIT, PUBLIC INTEREST LAW FIRM INCORPORATED IN 1974 TO SERVE HAWAIIANS. FIVE ATTORNEYS AND TEN STAFF MEMBERS WORK EXCLUSIVELY TO ASSERT, PROTECT AND DEFEND HAWAIIAN LAND AND TRADITIONAL RIGHTS. THE QUIET TITLE SERVICES ARE NOT FREE, BUT BY COMPARISON, THE COSTS ARE MINIMAL AND ARE RECOVERED ONLY IF NHLC IS SUCCESSFUL.

I WILL ADDRESS ONE MORE ISSUE, MR. CHAIRMAN, AND THAT WILL COMPLETE MY TESTIMONY. BUT THIS ISSUE IS AT THE VERY FOUNDATION OF OHA. IT IS A PRIMARY REASON FOR OHA'S CREATION, AND IT HAS TAKEN US TEN YEARS OF HIGH SPEED TRAVEL IN A FULL CIRCLE TO REACH THIS POINT.

I SPEAK OF THE ISSUE OF STATE ENTITLEMENTS DUE HAWAIIANS FROM REVENUE GENERATED BY THE USE OF CEDED LAND, OPERATION HO'OKULEANA. CEDED LAND IS WHAT REMAINS OF THE CROWN AND GOVERNMENT LANDS OF THE KINGDOM OF HAWAII, NOW UNDER THE JURISDICTION OF THE STATE OF HAWAII. IT IS LAW UNDER THE ADMISSIONS ACT OF THE STATE OF HAWAII THAT PART OF THOSE REVENUES ARE SET ASIDE FOR HAWAIIANS AS DEFINED UNDER THE HAWAIIAN HOMES ACT, THOSE OF 50% BLOOD QUANTUM. IN TEN YEARS, OHA HAS BEEN ABLE TO COLLECT ONLY A FRACTION OF THIS REVENUE FROM THE STATE.

OHA PETITIONED THE FORMER STATE ADMINISTRATION, TRIED JUDICIAL RELIEF AND FINALLY, THIS YEAR, OHA IS BACK AT THE LEGISLATURE. OHA TRUSTEES HAVE BEEN NEGOTIATING WITH THE GOVERNOR FOR TWO YEARS TO REACH AN ENTITLEMENT PACKAGE THAT WOULD BE FAIR TO HAWAIIANS WITHOUT BANKRUPTING THE STATE. THERE IS PRESENTLY A BILL IN THE LEGISLATURE ADDRESSING HAWAIIAN ENTITLEMENTS, AND WHILE THERE IS SUPPORT TO SETTLE THIS LEGAL ENTITLEMENT, DETAILS ARE STILL TO BE WORKED OUT.

AS I STATED EARLIER, MR. CHAIRMAN, THIS IS A CRITICAL POINT IN TIME FOR HAWAIIANS, AND OHA'S ROLE IS SIGNIFICANT. IN THREE YEARS, 1993, HAWAIIANS WILL OBSERVE THE 100TH ANNIVERSARY OF THE ILLEGAL OVERTHROW OF THE KINGDOM OF HAWAII. THE WORK WE ARE INVOLVED IN RIGHT NOW CLEARLY SETS THE STAGE FOR A CELEBRATION OF HAWAIIAN RECOVERY AND TRIUMPH OVER ADVERSITY.

Senator Inouye. I thank you very much, sir.

I think the record should show that the Office of Hawaiian Affairs is a quasi-government agency of the State of Hawaii. Chairman Kaulukukui was elected by the native Hawaiians of Hawaii, and he has served in this distinguished position during a most difficult time. And I wish to commend you for the work you have done, sir.

Mr. Kaulukukui. Thank you.

STATEMENT OF MASARU OSHIRO

Senator Inouye. Now, may I call upon the president and chief executive officer of Alu Like, Mr. Masaru Oshiro.

Mr. Oshiro. Thank you.

Senator Inouye, members of the panel, my name is Masaru Oshiro, president and chief executive officer of Alu Like. I want to thank you for the opportunity to present Alu Like's testimony on federally funded programs.

My testimony today will focus on the economic development programs for native Hawaiians. Historically Alu Like was founded in 1975 as a nonprofit community based agency serving the social and economic needs of Hawaiians statewide. This mission is pursued through four major programs of which employment and training, education, health and social services, and economic development are the major ones.

In 1988 a comprehensive needs assessment of native Hawaiian entrepreneurs was conducted and identified several major gaps in the business development service delivery system. Among the few gaps, a general lack of information and awareness by native Hawaiian businesses regarding the range of business development service that are available, a lack of specialized services and support aimed at helping to create new native Hawaiian business enterprises, the lack of business development services that adapt their promotion, outreach and service delivery methods to the cultural preferences and styles of native Hawaiians. There are others.

As a result of this study Alu Like established a native Hawaiian Business Development Center which houses our current two economic development projects. The first is the entrepreneurship training project which works in cooperation with the native Hawaiian evolving loan fund administered by the Office of Hawaiian Affairs.

The objective of this project is to provide training and education, to develop skills and techniques necessary for running successful businesses. We project assisting about 150 native Hawaiians this year.

Some of the participants are referred to us from the Office of Hawaiian Affairs, and in order to strengthen the linkage between our training program and the funding source OHA's revolving loan fund staff are irregularly invited to speak before the training classes.

The second project is the native Hawaiian business development project which is funded by the Administration for Native Americans, U.S. Department of Health and Human Services, projected his assistance to 81 native Hawaiians in the areas of business and financial planning as well as securing loans.

Alu Like also participates by serving under OHA's revolving loan fund board of directors. Our other federally funded programs include the 2 million adults employment and training programs and the 2.4 million summer youth programs through the Job Training Partnership Act. We are pleased to report that Alu Like again has surpassed all national performance standards established for this program.

This achievement is reflected in the appointment of our program administrator Winona Whitman to the National JTPA Native American Program Advisory Committee by the Secretary of Labor Elizabeth Dole. Other program summaries have been submitted as part of my testimony.

PREPARED STATEMENT

In closing I would like to note that for many native Hawaiians self-employment through business entrepreneurship presents an important and viable option to achieve economic self-sufficiency.

Thank you for the opportunity to testify.

[The statement follows:]

STATEMENT OF MASARU OSHIRO

Senator Harkin and members of the Subcommittee on Labor, Health and Human Services, Education, and Related Agencies, thank you for this opportunity to present testimony on ALU LIKE's Native Hawaiian, federally funded programs. My comments this morning will focus on economic development programs for Native Hawaiians.

ALU LIKE, Inc. was founded in 1975 as a non-profit, community-based organization serving the social and economic needs of the State's Native Hawaiian population. The Hawaiian population in our State comprises 20% or approximately 200,000 of the total State population.

ALU LIKE's mission is to assist Native Hawaiians in their efforts to achieve social and economic excellence. ALU LIKE pursues its mission through four major program areas of EMPLOYMENT and TRAINING, EDUCATION, HEALTH/SOCIAL SERVICES, and ECONOMIC DEVELOPMENT. For the purposes of this panel, I will direct my testimony to our programs which address economic development. For a more detailed description of ALU LIKE's remaining federally funded programs please refer to the written materials which are being submitted as part of this testimony.

ALU LIKE's efforts in the area of economic development are directed towards business development. In 1988, a comprehensive needs assessment of Native Hawaiian entrepreneurs was conducted. Several areas which represented major gaps in the business development service delivery system are:

1. A general lack of information/awareness by Native Hawaiian businesses regarding the range of business development services that are available.
2. A lack of specialized services and support aimed at helping to create new Native Hawaiian business enterprises.
3. A lack of basic education and training services to prepare new Native Hawaiian business owners and/or help existing business owners increase their management and entrepreneurial skills.
4. Insufficient access by Native Hawaiian firms and potential entrepreneurs to on-going financial, technical and management support in operating a new business.
5. Lack of business development services that adapt their promotion, outreach and service delivery methods to the cultural preferences and styles of Native Hawaiians.

As a result of this study, ALU LIKE established a Native Hawaiian Business

Development Center which houses our current two economic development projects. The first project which I would like to describe is the ALU LIKE **Entrepreneurship Training Project** which works in cooperation with the Native Hawaiian Revolving Loan Fund.

For program year 1989 this project received an internal grant of $195,000 from ALU LIKE's Vocational Education Program. The objective of this project is to provide vocational education services in the form of entrepreneurship training and education to assist Native Hawaiian adults in developing skills, attitudes, and techniques necessary to start and support successful business enterprises.

Our target group is 150 Native Hawaiian adults seeking to create or expand their own businesses. Training is delivered in the form of 1-day workshops held across the State and attended by 70 entrepreneurs. In addition, a 12 week intensive training course is in progress on the island of O'ahu and attended by 28 participants. This course will be repeated on four other islands across the State. A training course jointly sponsored by ALU LIKE and the SBA's Small Business Center will be held on the island of Hawai'i.

Some of the participants enrolled in the ALU LIKE entrepreneurship training course are referred to us from the Office of Hawaiian Affairs. These individuals are loan recipients who may need to develop their skills in business in order to ensure success. In addition, other students look to the Revolving Loan Fund as the most likely source of financing for their new start-up businesses. In order to strengthen the linkage between our training program and the financing source, a staff person from the Office of Hawaiian Affairs is invited to give a presentation to the class on the Revolving Loan Fund Program.

In 1991, the Entrepreneurship Training Project will address the continuing need for basic business education and assistance among the Native Hawaiian community. The objectives for PY 90 as well as the funding level required will therefore remain the same.

The second project I would like to describe is our Native Hawaiian Business Development project funded through a one year, $211,000 grant from the Department of Health and Human Services, Administration for Native Americans. The goal of this project is to assist 81 new and expanding businesses with preparing business plans, securing financing, and starting or expanding their businesses. In contrast to the Entrepreneurship Training Project which emphasizes a classroom learning situation, this project provides individualized counseling to businesses across the State. Many of these businesses, more accurately described as micro-enterprises, are located on islands other than O'ahu where business assistance services are extremely limited.

An underlying goal of the project is to provide assistance which will help Hawaiian entrepreneurs be more successful in accessing some of the sources of financing which are available through loan programs such as the OHA Revolving Loan Fund and other special State-sponsored loan programs. We are basically striving to provide these loan programs with more prepared and better qualified applicants. At this time approximately 45% of our 44 current clients are direct referrals from the Revolving Loan Fund project. Another 20% intend to approach OHA with their loan request. To date, ten of our clients have received loans, five from OHA and five from a State sponsored loan program.

Another way that ALU LIKE is able to support the Revolving Loan Fund project is through participating as a non-voting member of the policy making Board of Directors. This participation allows us to bring our knowledge of the needs of Hawaiian businesses to the attention of the Board.

While funding for this project will expire on September 30, 1990, the Revolving Loan Fund Program and other State sponsored programs will continue. We therefore see the need and demand for this type of business assistance only increasing. ALU LIKE will be exploring other avenues for funding of this project. To adequately address this need a minimum funding level of $200,000 is recommended.

There are a few remaining ALU LIKE federally sponsored programs which I would like to briefly mention.

Our Employment and Training program administers a $2 million adult job training project and a $2.4 million Summer Youth Program through the Job Training Partnership Act. During the past program year (PY88), ALU LIKE surpassed all of the performance standard measurements set by JTPA. By the end of the PY 88, our JTPA program assisted 1205 adults with completing their job training plans. The success of ALU LIKE's JTPA program is reflected in the appointment by Labor Secretary Elizabeth Dole of Winona Whitman, ALU LIKE Administrator to the National Job Training Partnership Act (JTPA), Native American Program Advisory Committee.

Within our JTPA program we have a special effort directed toward Native Hawaiian offenders and ex-offenders because of their overrepresentation in our prison system. During PY 88, we conducted 32 pre-employment workshops for incarcerated individuals, and 29 workshops for ex-offenders. By the end of the year 181 ex-offenders had been placed into employment, on-the-job-training or classroom training.

Included with the written materials accompanying this testimony is additional information on ALU LIKE's federally funded programs which I have not mentioned.

In closing I would like to note that while Native Hawaiians represent 20% of Hawaii's population, they comprise only 7% of minority-owned businesses in the State. Specially targeted programs such as the OHA Native Hawaiian Revolving Loan Fund, and ALU LIKE's two projects are much needed programs if these statistics are to change. For many Native Hawaiians, self-employment through business entrepreneurship presents an important and viable option.

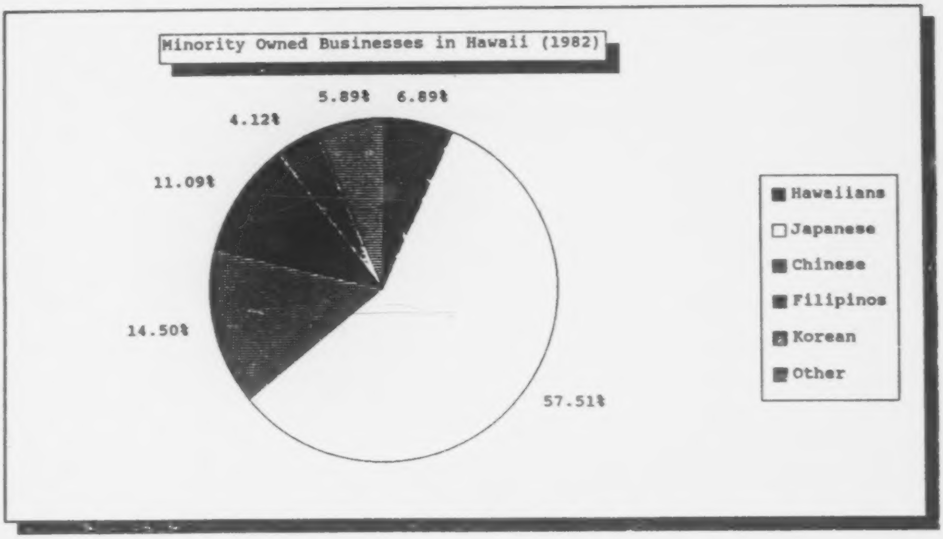
Senator Harkin and members of the Subcommittee, thank you for this opportunity to share ALU LIKE's economic development projects with you today.

EXHIBIT A

CURRENT PROGRAM STATISTICS

	1989 Program	Source
Employment and Training (JTPA) (Adult=$2,000,000) (Summer Youth=$2,400,000)	$4,400,000	DOL/DINAP
Vocational Education (Carl Perkins Act)	$2,100,000	DOE/Voc.Ed.
Ke Ola Pono Na Ke Kupuna (Older Americans Act, Title VI-B)	$1,400,000	DHHS/AoA
Native Hawaiian Elderly Needs Assessment	$100,000	DHHS/AoA
Library Services (Library Services Const. Act)	$612,000	DOE/OEIR
Business Development Project	$211,000	DHHS/ANA
FEDERAL TOTAL	**$8,823,000**	
State Dept. of Labor Matching Fund for ANA Business Dev. Grant	$30,000	State/DOL/OCS
Substance Abuse Prevention Project	$69,000	State/DOH/ADAB
Central Core Services	$430,000	State/DOL/OCS
Moloka'i Youth Center	$39,000	County of Maui
State/County Sub-total	**$568,000**	
TOTAL FUNDING LEVEL	**$9,391,000**	

EXHIBIT B



1982 Survey of Minority-Owned Businesses, U.S. Census Bureau

EXHIBIT C

NATIVE HAWAIIAN VOCATIONAL EDUCATION PROGRAM (NHVEP)
FISCAL YEAR 1990

A. Funding

In fiscal year 1990 (10/01/89 - 9/30/90), the NHVEP was allocated $2,092,555 to carry out its approved projects and activities.

B. Program and Project Objectives

As articulated when the NHVEP was first established in 1986, the major objectives of the program are the following:

- Improve the academic and employment skills of Native Hawaiian high school students and increase the number of graduates who pursue post secondary education or make a successful transition to the world of work.
- Increase the enrollment, retention, and completion rates of Native Hawaiian community college vocational education students.
- Establish vocational education services that will assist Native Hawaiian adults in becoming productive and upwardly mobile members of the labor force.

In addition to these broad program objectives, the individual project objectives are listed in Attachment A.

C. Status of Program and Project Objectives

The most recent external evaluation of the NHVEP, for fiscal year 1989, was carried out by Development Associates, Inc. based in Washington, D.C. Attachment B is an extract from that evaluation report and indicates that all project activities have been implemented in accordance with the grant submitted to the U.S. Department of Education. The external evaluation report also comments on the overall effectiveness of the NHVEP in the following terms:

- The program is well managed and the staff are well qualified and function effectively as a team. Staff vacancies during the year have caused minor problems, but to date this has not been a serious concern. While it is important that professional vacancies be filled relatively soon by qualified individuals, the openings have provided a useful opportunity to review staff functions and needs.
- The program's newly articulated mission statement and five program goals (see Chapter III) reflect the legitimate needs and concerns of the Native Hawaiian community, and capture, in the most comprehensive sense, the program's overall purpose of achieving parity for Native Hawaiians with respect to participation in and obtaining benefits from an improved vocational education system.
- The NHVEP has continued to evolve into a highly comprehensive and systematic program, with eight major projects implemented and two projects at the secondary school level under development. The current efforts to expand work at the secondary school level are appropriate and greatly needed. These two demonstration projects will significantly expand the program's necessary and challenging process of helping to strengthen the secondary school vocational education program throughout the islands.

NATIVE HAWAIIAN VOCATIONAL EDUCATION PROGRAM (NHVEP)
FISCAL YEAR 1991

A. Needs

Besides the continuation of existing NHVEP projects, there are several major needs facing the program in fiscal year 1991 and beyond.

1. Expansion of High School Projects. In fiscal year 1990, the NHVEP initiated two vocational education projects at the high school level. One focuses on improving the counseling and guidance programs at high schools to increase the number of Hawaiian students going on to college. The other focuses on restructuring and revitalizing the vocational education curriculum to ensure that Hawaiian students are equipped with the academic, cognitive, and

interpersonal skills needed for success after graduation.

Funding limitations have meant that these projects can only be installed in 2 of Hawaii's 38 public high schools. Expansion to other schools with large percentages of Hawaiian students would require additional moneys. For instance, to install these projects at 10 more schools would require $817,135.

2. Establishment of an Information and Educational Training Center. Many of the NHVEP-funded projects are pilot projects the object of which is to demonstrate and replicate new approaches to educating Native Hawaiian youth. As these projects are evaluated and refined, it becomes increasingly important to understand what has made them effective and to promote the use of these successful approaches throughout the State. Accordingly, the NHVEP external evaluator has recommended that in FY 1991 consideration be given to the creation of an Information and Educational Training Center in conjunction with the NHVEP. The three basic purposes outlined for the Educational Training Center by the external evaluator are listed in Attachment C. The estimated annual cost of operating such a Center is $250,000.

3. Other Areas of Concern. Although the NHVEP has developed a broad-based set of activities, there are still areas in which expansion would be of considerable benefit to Native Hawaiian youth and adults. These areas include summer enrichment activities, school-to-work transition assistance, and career development services for adults. A conservative estimate of the funds required to address the needs of Native Hawaiians in these areas is $500,000.

B. Proposed Program and Project Objectives

As the NHVEP has evolved, its overall objectives have been re-examined and revised to meet changing needs, capabilities, and circumstances. Objectives that will govern NHVEP activities for FY 1991 and beyond are the following:

1. Design, pilot, and evaluate educational interventions that are effective in promoting higher achievement levels among Native Hawaiian vocational education students so as to institutionalize those practices which have been successful in secondary and post-secondary institutions.

2. Increase the awareness of educational policy makers and practitioners of the needs of Native Hawaiian vocational education students and the adoption of practices that have proven successful in meeting these students' needs.

3. Design, pilot, evaluate, and institutionalize within the private sector educational interventions that are effective in promoting career advancement prospects or capabilities for self-employment for Native Hawaiians already in the labor force.

4. Establish partnerships with schools, colleges, community-based organizations, and the private sector that will assist Native Hawaiians in selected low socio-economic communities in benefiting from new employment opportunities resulting from regional economic development activities.

5. Establish and maintain an information and training center to assist educators of Native Hawaiian youth and adults to more effectively equip Native Hawaiians with the academic and vocational skills necessary for productive and satisfying employment.

C. Funds Needed

The need areas cited above would necessitate an additional $1,567,135 of funds for the NHVEP in addition to the $2,092,555 received in fiscal year 1990.

ATTACHMENT A

NHVEP Projects List, PY 89 (10/01/89 - 9/30/90)

AGENCY	PROJECT TITLE	OBJECTIVE	TARGET GROUP	BUDGET
Office of Instructional Services State Dept. of Education	Hana Kupono	Improve students' mastery of basic academic and cognitive skills.	Native Hawaiian intermediate school students (13 schools).	$272,276.00
Office of Instructional Services State Dept. of Education	Career Education Demonstration Project	Improve students's career aspirations and knowledge of the world of work.	Native Hawaiian intermediate school students (2 schools).	$105,244.00
Windward District State Dept. of Education	E Kulia I Ka Nu'u	Improve counseling and guidance services to increase the number of students enrolling in community colleges.	Native Hawaiian high school students (2 schools).	$103,227.00
Leeward District State Dept. of Education/ Center for the Advancement of Pacific Education	Leeward District Vocational Education Improvement Project	Upgrade vocational education programs and services to enable students to capitalize on regional economic development activities.	Native Hawaiian high school students (2 schools).	$ 60,200.00
Office of Instructional Services State Dept. of Education	Senior Career Intern Program	Provide summer internships in the private sector for students wishing to pursue business careers.	Native Hawaiian high school seniors.	$ 19,471.00
Office of the Chancellor for Community Colleges University of Hawaii	Native Hawaiian Vocational Education Project	Increase the enrollment, retention, and completion rates of Native Hawaiians in the community colleges.	Native Hawaiian high school graduates, community college enrollees, and returning adults.	$101,689.00
Hawaii Community College	Native Hawaiian Vocational Education Project	Increase the enrollment, retention, and completion rates of Native Hawaiians in the community colleges.	Native Hawaiian high school graduates, community college enrollees, and returning adults.	$ 81,468.00
Honolulu Community College	Native Hawaiian Vocational Education Project	Increase the enrollment, retention, and completion rates of Native Hawaiians in the community colleges.	Native Hawaiian high school graduates, community college enrollees, and returning adults.	$ 37,281.00
Kapiolani Community College	Native Hawaiian Vocational Education Project	Increase the enrollment, retention, and completion rates of Native Hawaiians in the community colleges.	Native Hawaiian high school graduates, community college enrollees, and returning adults.	$ 97,807.00

NHVEP Projects List, PY 89 (10/01/89 - 9/30/90)

AGENCY	PROJECT TITLE	OBJECTIVE	TARGET GROUP	BUDGET
Kauai Community College	Native Hawaiian Vocational Education Project	Increase the enrollment, retention, and completion rates of Native Hawaiians in the community colleges.	Native Hawaiian high school graduates, community college enrollees, and returning adults.	$ 52,788.00
Leeward Community College	Native Hawaiian Vocational Education Project	Increase the enrollment, retention, and completion rates of Native Hawaiians in the community colleges.	Native Hawaiian high school graduates, community college enrollees, and returning adults.	$ 44,307.00
Maui Community College	Native Hawaiian Vocational Education Project	Increase the enrollment, retention, and completion rates of Native Hawaiians in the community colleges.	Native Hawaiian high school graduates, community college enrollees, and returning adults.	$ 81,520.00
Hawaiian Educational Council, Inc.	Program for Occupational Skills Training (POST)	Improve the ability of Native Hawaiian entry-level employees in selected private sector firms to improve their prospects for career advancement.	Native Hawaiian entry-level workers.	$ 95,236.00
ALU LIKE, Inc.	Hawaii Computer Training Center	Provide computer skills training to unemployed Native Hawaiian adults.	Native Hawaiian adults.	$325,410.00
ALU LIKE, Inc.	Native Hawaiian Business Development Center	Assist Native Hawaiian adults in developing the skills, attitudes, and techniques necessary to start their own business enterprises.	Native Hawaiian adults.	$194,515.00
Kailua-Waimanalo Community Education Coalition	Parent Involvement in Education	Increase Native Hawaiian parent and community involvement in schools in the Kailua-Waimanalo area.	Parents and residents of the Kailua-Waimanalo area.	$ 43,243.00

ATTACHMENT B

EXHIBIT 2

ACCOMPLISHMENTS AND PLANS OF NHVEP PROJECTS FUNDED IN 1986-1989

Project	Brief Summary of Accomplishments in 1988-89	Evaluation in 1988-90	Plans for 1989-90	Objectives for 1989-90
Hana Kupono	Implemented activities in accordance with grant and served approximately 800 students	Evaluated by the U.H. College of Education	Continued implementation in the same 13 schools	o Increase student skills in reading, writing, math, etc. o Improved student attitudes toward school
Community College	o Completed design of computerized student tracking system o Implemented activities in accordance with NHVEP grant	Evaluated by Comm. College and NHVEP Staff using enrollment and retention data	o Addition of the 7th community college in UH system o Will be the first full year UH provides staff for implementing grant activities	o Increase N.H. enrollment and retention o Continue institutionalization of project activities with the UH system
Career Education	Implemented activities in accordance with grant and served approximately 300 students	Evaluated by a private firm	Continued implementation at the 2 target schools	Improve students' career knowledge and skills in math
POST	o Completed initial needs assessment o Provided 3 months of training at 2 companies o Implemented other grant activities in accordance with plans	None conducted with summary report completed by grant staff	Continued implementation and employment of evaluation design	o Increase support of workplace literacy efforts by local corporations o Increase participants' skills and employment benefits
Computer Training Center	Implemented activities in accordance with grant and served required number of students (i.e., 100)	Evaluated by the Northwest Educational Laboratory	o Possible expansion to neighbor islands o Continued implementation of training o Summer program funded by IBM	o Training and placement of approximately 100 adults o Increased financial self-sufficiency for the center
Business Development Center	o Center is open and in operation o 2 course cycles completed as pilots o Secured funding from ANA	Implementation of pilot cycles and evaluated by a private firm	o Expand to neighbor islands o Continued implementation of training o Follow-up of students	o Increase participants' skills and increase N.H. use of business support services o Increased financial self-sufficiency
Kailua-Waimanalo Community Coalition	o Coalition organized and functioned o Prepared community resource directory o Developed community workshops and newsletter	None conducted	Increase coordination with state mandated school-based management efforts	o Resolve relationship issues between K.W. Coalition and school-based management council o Design and implement school improvement activities
Career Intern	Completed program for 12 interns	Evaluated by the Hawaiian Education Council	Increase number of interns served to 25	o Finalize design so the program can be replicated and expanded o Improve students skills and attitudes

ATTACHMENT C

PROPOSED OBJECTIVES FOR THE NHVEP INFORMATION AND EDUCATIONAL TRAINING CENTER

Developing and coordinating the implementation of a NHVEP strategy for institutionalizing programs and practices which have been found to be effective with Native Hawaiians within the established Hawaiian education and training institutions. Such a strategy would include:

- o identifying appropriate target institutions;
- o specifying groups and individuals associated with targeted institutions which need to be informed and assisted in order for effective programs or practices to be incorporated into on-going operations;
- o identifying relationships among institutions, group and individuals which will effect the receptivity of target institutions;
- o specifying particular policies, programs and practices on which NHVEP will concentrate its information and training activities; and
- o specifying the means of disseminating information and accessing target individuals and institutions on which NHVEP will concentrate.

Assembling, packaging and disseminating information regarding the education and training policies, programs and practices which will benefit Native Hawaiians. Activities associated with this function would include:

- o identifying the essence of effective policies, programs and practices associated with NHVEP funded projects;
- o assembling information about effective policies, programs and practices beyond those supported by NHVEP (e.g., other ALU LIKE programs, Kamehameha Schools, etc.);
- o preparing useful descriptions of the process and results of implementing effective policies, programs or practices for policy and practitioner audiences; and
- o disseminating information on effective policies, programs and practices through print and other media, meetings and conferences, and other appropriate means.

Coordinating the provision of training and technical assistance with respect to effective policies, programs and practices. Activities associated with this function should include:

- o stimulating demand for training and assistance with respect to implementing effective policies, programs and practices from individuals and groups associated with the targeted institutions;

- identifying resources which can provide high quality training and technical assistance; and
- coordinating the delivery of training and assistance activities.

Graph A

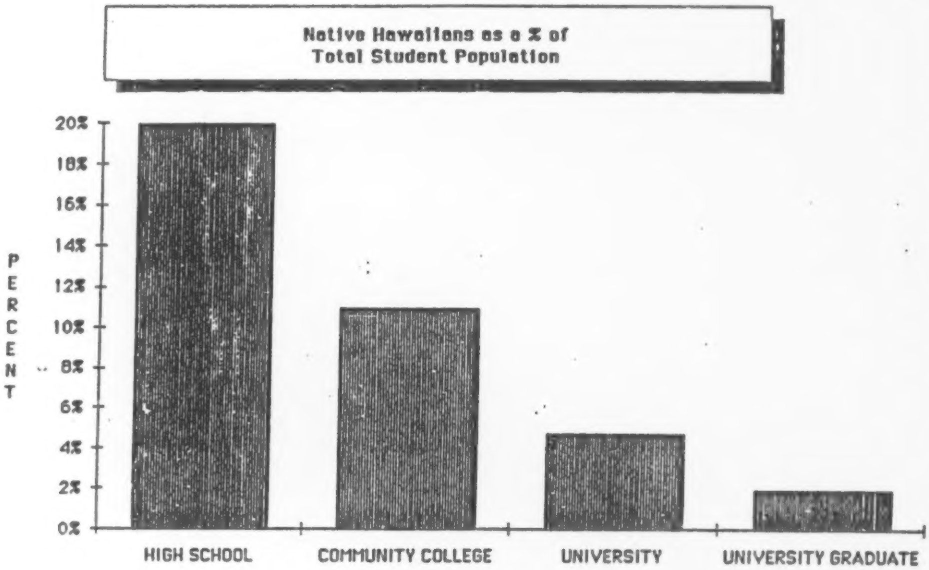


EXHIBIT D

STATUS OF NATIVE HAWAIIANS IN THE PUBLIC EDUCATION SYSTEM

Data collected by the Hawaii State Department of Education and the University of Hawaii indicate that Native Hawaiian participation in the public education system progressively declines in the advance from elementary and secondary schools to university graduation.

Graph A on the following page illustrates Native Hawaiian representation as a percent of total student population at four points in the educational continuum.

- According to 1986-87 DOE figures, Native Hawaiians represent about 22.3 percent of total K-12 public school enrollment (i.e., 36,926 students out of a total of 165,943). For grades 9-12 only, Native Hawaiians represent about 20 percent of total public school enrollment (9,478 students out of 47,478).
- University of Hawaii figures for the Fall Semester, 1986, show that Native Hawaiians represent 10.9 percent of total community college enrollment at the seven campuses cited in the preceding section (2,227 students out of a total of 20,342).

- University of Hawaii figures for Fall, 1987 indicate that Native Hawaiians represent approximately 5.1 percent (929 students out of 18,382) of total student enrollment at the University of Hawaii-Manoa, the major 4-year campus in the UH system.
- University of Hawaii data for 1977-84 indicate that Native Hawaiians represented only 2 percent of students who graduated from the University of Hawaii-Manoa during this time.

Thus, there is clear evidence that Native Hawaiian representation in the public education system deteriorates markedly at each successively higher level of educational attainment.

STATUS OF NATIVE HAWAIIANS IN THE PUBLIC VOCATIONAL EDUCATION SYSTEM

Although there is a need for more detailed information on the status of Native Hawaiians in the public vocational education system, available data point to the same general trend that was cited above - progressively declining Native Hawaiian participation at each successively higher level of educational attainment.

- High School to Community College Transition. According to DOE figures for the 1986-87 school year, Native Hawaiians represented about 33.8 percent of all students enrolled in high school vocational education courses (8,593 enrollees out of a total of 25,414). However, for the 1987 Fall Semester, Native Hawaiian enrollment in community college vocational education courses represented only 11.8 percent of total community college vocational education enrollment (911 out of 7,724). These figures indicate that there is a precipitous decline in Native Hawaiian vocational education participation between high school and community college and that Native Hawaiians face serious obstacles in making the transition from one level to the other.
- Retention in and Completion of Community College Programs
  As will be discussed later in this proposal, a major educational issue in the United States is the exceptionally high dropout rate among community college students. The American College Testing (ACT) Program reports that the freshman to sophomore year dropout rate for two-year public institutions is 47.8 percent, by far the highest dropout rate for any of the types of postsecondary educational institutions in the United States.

  A cohort analysis conducted for the NHVEP by the University of Hawaii Community Colleges shows that the dropout rate for Native Hawaiian students is even higher than the national figure. Of the 1,003 Native Hawaiian students who registered as freshmen in the Fall 1982 semester, 631 did not re-enroll for the Fall 1983 semester. This year-to-year drop out rate of 63% considerably surpasses the national figure for community college students reported above. The figures for vocational education students alone were only moderately better. Of the 1,003 Native Hawaiian students identified in the UHCC cohort analysis, 453 were registered as vocational education students. Of these 453, 253 did not re-enroll for the Fall 1983 semester for an overall drop out rate of 56%. Finally, the UHCC cohort analysis shows that of the 1,003 Native Hawaiian students, only 84 had graduated (i.e., received a certificate or degree) by the Fall 1986 semester. Thus, the retention and completion of Native Hawaiian students in the postsecondary vocational education system ranks as an important consideration of the NHVEP.

- Program Enrollment Patterns. In addition to the evidence documenting declining Native Hawaiian participation in vocational education at successively higher levels of educational attainment, Native Hawaiian program enrollment patterns have also been analyzed and interpreted as further evidence of unequal participation in the public vocational education system.

Program/ Institution	Total Enrollment	Native Hawaiian Enrollment	Native Hawaiian Enrollment as a % of Total Enrollment
Agriculture, Hawaii C.C.	60	19	31.67%
Agriculture, Maui C.C.	71	22	30.99%
General Office Training, Maui C.C.	113	23	20.35%
Data Processing, Kapiolani C.C.	569	45	7.91%
Electronics, Honolulu C.C.	554	43	7.76%
Accounting, Kapiolani C.C.	456	31	6.80%
Computer Science, Leeward C.C.	509	33	6.48%
Associate Degree Nursing, Maui C.C.	61	3	4.92%

It has been suggested that high Native Hawaiian enrollment in programs such as agriculture and general office training and low enrollment in programs such as electronics and computer science may be due to (1) ethnic occupational stereotyping on the part of counselors and other academic advisors who thus "track" Native Hawaiians into certain types of programs; or (2) lack of reading, writing, and computational skills needed to foster student confidence and success in disciplines requiring sophisticated analytical and problem-solving abilities. Whatever the explanation may be for these enrollment patterns, it has been argued that they represent a form of unequal participation in the public vocational education system since Native Hawaiians do not appear to have truly equal access to all vocational education programs available in the community colleges. More investigation into the causes of these enrollment patterns will be conducted in the 1988-89 program year.

EXHIBIT E

NATIVE HAWAIIAN LIBRARY PROJECT Information Requested

For current appropriations year (October 1989 - September 1990)

a. AMOUNT OF FUNDS RECEIVED

$612,175

b. PROGRAM/PROJECT OBJECTIVES

See attachment A

c. STATUS ON COMPLETION/ACHIEVEMENT OF STATED OBJECTIVES

See attachment B

For next year appropriations year (October 1990 - September 1991)

a. DESCRIPTION OF NEEDS

See attachment C

b. PROPOSED PROGRAM/PROJECT OBJECTIVES TO MEET NEEDS

See attachment A

c. FUNDS NEEDED TO IMPLEMENT PROGRAM/PROJECT TO MEET NEEDS

$950,000
See attachment D
See Attachment E

Attachment A

MISSION AND OBJECTIVES
OF THE
NATIVE HAWAIIAN LIBRARY PROJECT

Mission Statement:

Significantly improve access to information services to Native Hawaiians in an effort to increase their educational achievement.

Objectives:

I. Increase the availability of library resources by providing cultural, historical, and informational resources appropriate to Native Hawaiian needs and interests.

II. Support and encourage parent/child programs which create an awareness of the value of reading to young children.

III. Increase the use of libraries by Hawaiians for the purpose of life-long learning.

IV. Strengthen library skills of adult Hawaiians whose reading and writing skills are not at a functional level.

V. Provide employment opportunities for Native Hawaiians in library and information services.

VI. Increase librarians', teachers', and researchers' awareness and appreciation of Hawaiian resource materials.

VII. Gather needs assessment data to guide ongoing planning and program development.

Attachment B

STATUS ON COMPLETION OF OBJECTIVES FOR PROGRAM YEAR 1989-1990

I. Increase the availability of library resources by providing cultural, historical, and informational resources appropriate to Native Hawaiian needs and interests.

LIBRARY RESOURCE VAN
Holomua Resource Van - A new resource van was purchased with insurance claims reimbursements from the insurance company that held the policy on the original van. The new van replaces the resource van destroyed in the Young Brothers barge fire on April 18, 1989. It is a new 1989 GMC Safari van with air conditioning.

Lecture Series - A series of lectures has been planned and scheduled for the program year to present topics of interest to Hawaiians in public libraries The series has been given a Hawaiian name, "Ohina Moolelo Maikai", or exchange of ideas, to detract form the negative connotation that the term lecture series may have to our intended population. The first lecture, "How to start your family's genealogical search," was held at Waimea Public Library on Kauai.

Traveling Exhibit - Two traveling exhibits have circulated to public libraries this quarter. The Surfing exhibit, designed to appeal to young adults, was displayed for one month at Kealakekua Public Library, Pahala Public Library, and Hilo Regional Public Library on the island of Hawaii. The Kahoolawe exhibit circulated to Kahului Public Library, Makawao Public Library, and Lahaina Public Library on the island of Maui.

BOOKS BY MAIL PROJECT
Total circulation for this project was 3,427 library materials this quarter. The project serviced 1,339 library patrons.

HOMEWORK CENTER PROJECT
This project serviced 3,854 patrons and circulated 3,437 library materials.

SITES DATA BASE
The sites data index completed during past program years has been reviewed to determine the scope of services required to complete this five year project.

II. Support and encourage parent/child programs which create an awareness of the value of reading to young children.

PARENT WORKSHOPS
Nine parent child reading workshops were conducted which serviced 423 participants.

III. Increase the use of libraries by Hawaiians for the purpose of life-long learning.

LIBRARY PROMOTIONS PROJECT
A video tape has been produced to encourage seeking literacy services to improve reading skills. This video has aired on public television in Hawaii.

IV. Strengthen library skills of adult Hawaiians whose reading and writing skills are not at a functional level.

LITERACY PROJECT
The draft copy of the brochure to support the Sticks and Stones video has been completed and sent to the printer. Volunteers have been trained to use the literacy video tape as part of their presentation at three DHS intake centers on Oahu.

V. Provide employment opportunities for Native Hawaiians in library and information services.

LIBRARY STUDY FELLOWSHIP
Two students are attending the University of Hawaii Graduate School of Library and Information Studies.

VI. Increase librarians', teachers', and researchers' awareness and appreciation of Hawaiian resource materials.

HAWAIIAN AND PACIFIC COLLECTION UPDATE
Hawaiian Resource Materials produced by the project during the last program year have been catalogued and distributed to the public library system and libraries with a Hawaiian collection.

VII. Gather needs assessment data to guide ongoing planning and program development.

NEEDS ASSESSMENT
Discussion has been initiated with people and agencies that will be involved in the planning for the needs assessment to be conducted this program year.

Attachment C

Need Categories

Need Category I: Library Usage

a) Under-utilization of existing resources and services by Hawaiians is a problem. This is reflected in the low circulation data gathered from communities with high concentration of Hawaiians and compared with other rural communities with similar bookstacks and services. (Masae Gotonda - State Library Office Research and Education)

b) Numerous Hawaiians stated that they were not skillful library users and thus did not feel comfortable in traditional libraries. (Community Forums)

c) Hawaiian adults with poor reading skills find it difficult to support and encourage reading and the academic programs of their children. (Community Forums)

Need Category 2: Access To Library Service

a) The distance to libraries and the existing library service hours make it difficult to fully utilize the services of the library system. (Community Forums)

Need Category 3: Lack of an awareness and understanding of library services and programs.

a) Many Hawaiians do not recognize the broad scope of resources and services available in libraries which can meet their educational, informational, and recreational needs. (Community Forums)

Need Category 4: Lack of Culturally-Based Library Resources Available for Youth and Adults in Professional Fields

a) All seven Dept. of Education School districts reported there is a gap in the area of library resources in Hawaiian Studies suitable for use by younger students from pre-school through grade 8. This is a gap area not only for Hawaiians but for all of Hawai'i's children. (OHA Survey-CSHO and Interviews with Teachers and Childrens Librarians)

b) There are too few items published, printed or created concerning Native Hawaiian history, culture and the arts. Demand for knowledge exceeds the resources available. (Bart Kane - State Librarian)

c) Hawaiians expressed a need for materials in the Hawaiian language. (Community forums)

Need Category 5: Lack of Adequate Resource Material

a) Library books, magazines, music and films about Native Hawaiians are the most popular items in the library system. Libraries have too few copies of these items for the public to use. (Bart Kane - State Librarian)

b) Hawaiians expressed frustration about the reference designation on so much of the Hawaiian resource material and the lack of circulating copies available. (Community Forums)

Need Category 6: Strengthening adult Literacy Skills

Hawaiian adults expressed a need to develop and strengthen their literacy skills. (Community forums)

Need Category 7: Underrepresentation of Hawaiians in Library Professional Occupations

Only six part-Hawaiian professional librarians have been identified one hundred seventeen in the public library system. Identification among the paraprofessional staff has not been done.

Need Category 8: Lack of Adequate Needs Assessment Data

The Public Library Office of Research and Evaluation has not planned programs or evaluated services on the basis of ethnicity. Thus there is little assessment data available except what was gathered in the nineteen forums conducted in Hawaiian communities statewide.

Attachment D

Filename: 90bgtsum

ALL WHLP
FY 90 BUDGET SUMMARY

Project No.	1 Resource Van	2 Lecture Series	3 Traveling Exhibit	4 Books-by-Mail	5 Parent Workshops	6 Reading Encourgmt	7 Homework Centers	8 Library Promotion	9 Literacy Support	10 Fellowships	11 Lib Study Contin Ed	12 HResource Workshops	13 Lib Needs Assessmt	14 Info Mgt System	15 H Myths & Legends	16 H&PCollect Update	COST POOL	ADMIN	TOTAL
Personnel	$49,830	$6,300	$6,300	$25,991	$20,724	$15,398	$41,691	$6,800	$16,625	$0	$0	$0	$0	$0	$0	$0	$37,263	$78,921	$307,844
Fringe	$9,223	$1,281	$1,281	$4,749	$3,599	$2,920	$6,503	$1,320	$3,076	$0	$0	$0	$0	$0	$0	$0	$6,665	$12,935	$53,554
Travel	$2,600	$2,600	$2,600	$1,800	$1,300	$1,040	$5,400	$0	$0	$0	$0	$0	$0	$0	$0	$0	$0	$9,040	$26,380
Equipment	$2,700	$0	$0	$2,000	$0	$0	$21,300	$0	$4,100	$0	$0	$0	$0	$7,000	$0	$7,000	$4,000	$5,300	$53,400
Equipment Maintenance	$4,000	$0	$0	$0	$0	$0	$0	$0	$0	$0	$0	$0	$0	$0	$0	$0	$7,000	$3,000	$14,000
Supplies	$2,000	$1,000	$1,000	$2,500	$1,500	$2,000	$2,400	$0	$500	$0	$0	$0	$0	$0	$0	$0	$0	$600	$13,500
Contractual	$1,500	$1,000	$500	$0	$0	$0	$0	$26,083	$0	$0	$0	$1,520	$23,014	$29,200	$8,440	$0	$0	$16,000	$105,257
Library Materials	$23,965	$3,000	$3,000	$5,000	$3,500	$13,000	$10,000	$0	$2,000	$0	$0	$0	$0	$1,000	$0	$83,311	$0	$0	$147,776
Other	$16,400	$150	$10,600	$0	$200	$0	$1,800	$0	$0	$21,224	$2,280	$0	$0	$0	$0	$0	$60,500	$22,498	$135,740
Total Project	$114,218	$15,331	$25,281	$42,039	$30,823	$34,358	$89,093	$34,203	$26,301	$21,224	$2,280	$1,520	$23,014	$37,200	$8,440	$90,311	$115,518	$148,496	$859,650
Indirect	$14,763	$1,895	$1,895	$7,685	$6,081	$4,579	$12,048	$2,530	$4,925	$0	$0	$0	$0	$0	$0	$0	$10,983	$22,964	$90,350
Total Costs	$128,982	$17,227	$27,177	$49,724	$36,904	$38,937	$101,142	$36,733	$31,227	$21,224	$2,280	$1,520	$23,014	$37,200	$8,440	$90,311	$126,501	$171,458	$950,000

Attachment E

AUTHORIZED ACTIVITIES BY PROJECT

1. Assessment of Hawaiian native library needs.

    90.13 Library Needs Assessment
    90.14 NHLP Information Management System

2. Inservice or preserve training of Hawaiian natives as library personnel.

    90.10 Library Study Fellowships
    90.11 Library Study - Continuing Education
    90.12 Hawaiian Resources Workshops

3. Salaries of library personnel.

    90.01 Library Resource Van
    90.04 Books By Mail
    90.05 Parent Workshops
    90.06 Reading Enrichment
    90.07 Homework Centers
    90.12 Hawaiian Resources Workshops

4. Purchase of library materials.

    90.01 Library Resource Van
    90.02 Library Lecture Series
    90.03 Traveling Library Exhibit
    90.04 Books By Mail
    90.16 H&P Collection Update
    90.05 Parent Workshops
    90.06 Reading Encouragement
    90.07 Homework Centers
    90.09 Literacy Support

5. Dissemination of information about library services.

    90.01 Library Resource Van
    90.02 Library Lecture Series
    90.04 Books By Mail
    90.05 Parent Workshops
    90.06 Reading Enrichment
    90.07 Homework Centers
    90.08 Library Promotions
    90.12 Hawaiian Resources Workshops

6. Conduct of special library programs for Hawaiian natives.

    90.01 Library Resource Van
    90.02 Library Lecture Series
    90.03 Traveling Library Exhibit
    90.04 Books By Mail
    90.15 Myths and Legends Through Puppetry
    90.05 Parent Workshops
    90.06 Reading Encouragement
    90.07 Homework Centers

7. Contracts to provide public library services to Hawaiian natives, or to accomplish any of the above activities.

    90.15 Hawaiian Myths and Legends through Puppetry
    90.12 Hawaiian Resources Workshops
    90.13 Library Needs Assessment
    90.14 NHLP Information Management System

EXHIBIT F

JTPA PERFORMANCE MEASURES, PY 1988

Reference: DINAP BULLETIN NO. 89-15
Subject: Final PY 88 Performance Standards Result for JTPA Section 401 Program Grantees

Background

JTPA performance measures are established by the following three criteria:

Entered Employment Rate
Positive Termination Rate
Cost per Positive Termination Rate

ALU LIKE JTPA PROGRAM FOR PY 88 (July 1988 to June 1989)

Entered Employment Rate		
Total Terminations	1325	
Total Entered Unsubsidized Employment	1029	
Actual Entered Employment Rate (EER)		77.7%
Positive Termination Rate		
Total Terminations	1325	
Total Positive Terminations (entered employment plus additional positive terminations)	1205	
Actual Positive Termination Rate (PTR)		90.9%
Cost per Positive Termination		
Total Terminations	1325	
Total Positive Terminations	1205	
Actual Cost per Positive Termination (CPT)		$1671

JTPA/DINAP PREFORMANCE STANDARD MEASURES FOR ALU LIKE

EER EXEMPLARY	73.9	PTR EXEMPLARY	94.1	CPT EXEMPLARY	$2684
EER GOAL	59.6	PTR GOAL	84.3	CPT GOAL	3556
EER MINIMUM	45.3	PTR MINIMUM	74.5	CPT MINIMUM	4428

EXHIBIT G

INFORMATION SHEET

Project Title: Ke Ola Pono Na Ke Kupuna
(Good Health and Living for the Elderly)

Funded By: Administration on Aging, U.S. Dept. of Health and Human Services

Amount: $1,364,359

Project Period Oct. 1, 1989 - Sept. 30, 1992

Location: Hawai'i, Kaua'i, Maui, Moloka'i, O'ahu

Target Group: 250 Native Hawaiian elderly aged 60 and over

Staffing: Project Administrator, Program/Contract Specialist, Registered Dietician, Fiscal Officer, 5 Site Coordinators, Research Assistant, Project Secretary, Cook, 6 Outreach Workers

Program Area: Health and Social Services

Description of Project: The purpose of the project will be to provide:

- community-based center for project administration (Lunalilo Home)
- nutrition services and meals
- access services which cover transportation, information and referral, and outreach services
- health enhancement including health screening and assessment, self care training and recreation, and education services
- other support services planned for subsequent years such as legal assistance, counseling, individual case coordination and management, in-home care, and personal care services.

Evaluation: There will be two general strategies for evaluation: a) presentation of descriptive statistics and b) measurement of goals/objectives fulfillment.

Contact: Dawn Noguchi, Project Administrator
Haunani Apoliona, Director Program Operations
Masaru Oshiro, CEO

Senator Inouye. I thank you very much, Mr. Oshiro.

I think the record should show that at the time when these job training programs were being plagued with scandal in many parts of this land, the program by Alu Like was the most outstanding in the United States. It has throughout its life surpassed all of the requirements set forth by the national government and no other agency can say the same.

And the results have been outstanding, and I commend you and your organization for the work you have done. I wish you God speed in your future endeavors.

Mr. Oshiro. We thank you for your support.

STATEMENT OF RICHARD PAGLINAWAN

Senator Inouye. And now may I call upon the administrator of the Office of Hawaiian Affairs. Do you wish to testify, sir? Mr. Paglinawan.

Mr. Paglinawan. Hello, Mr. Chairman and members of the committee. I would also like to add, Senator, my personal greeting to you for your initiatives in helping the native Hawaiians, particularly, in the area of health, economic development, and education. But most recently, in terms of your trying to address the Hawaiian Homelands Commission Act.

As you know, Congress has neglected this program for approximately 6 to 8 years, and we appreciate your effort in this area.

I am Richard Paglinawan, administrator of the Office of Hawaiian Affairs, and it is my pleasure to be here today to make this presentation on behalf of OHA.

I have been asked to focus on economic development for Hawaiians and I will do that. But first a couple of brief remarks.

Mr. Chairman, the Office of Hawaiian Affairs has only a few Federal grants, but each has been memorable. The grant for self-help housing from the Department of Health and Human Services Administration for native Americans in 1987 was matched by the Office of Foreign Affair Funds and set a major precedent as the first self-help housing project to be attempted on Hawaiian homestead land.

Although that particular grant has been complete, OHA continues to assist the Department of Hawaiian Homelands though with another funding source for self-help housing. In 1988 I am proud to say the U.S. Department of Education ranked OHA's substance abuse prevention education grant proposal No. 1 of 296 applicants across the country and, we receive approximately $113,000.

OHA added another $36,000 of its own funds and embarked on a joint educational effort with the Castle Medical Center, the Honolulu Police Department, and the State Department of Education. This project was so successful that it has been extended and expanded to a larger scale in additional islands.

Our largest Federal award to date is $3 million, has also been from the Administration for Native Americans to administer the native Hawaiian revolving loan fund. These funds are being used for Hawaiian economic development through business loans to start, expand or improve businesses owned by Hawaiians, who are unable to obtain loans through conventional means.

You will be pleased to hear, Mr. Chairman, that every bit of the Federal grant money goes to our beneficiaries, because the Office of Hawaiian Affairs is funding all of the administrative cost. This project has been specifically designed to promote economic independence and self-sufficiency among Hawaiians.

In addition to providing loans, project staff give technical assistance to each loan recipient to help improve their business and achieve financial success. When it is appropriate, assistance is also provided by the Bank of Hawaii, the U.S. Business Loan Administration, the Chamber of Commerce of Hawaii, and the University of Hawaii Small Business Management Program.

The closest agency alliance, of course, is with Alu Like. Loans are made for a maximum of 5 years. By law the interest rate will be 2-percent below the Treasury bill rate at the time of loan approval. The business for which the loan is made must be 100 percent Hawaiian owned. Individuals, nonprofit organizations, cooperative associations, partnerships, and corporations are all eligible as long as all the owners or partners are of Hawaiian ancestry.

Alu Like has identified several gap areas in Hawaiian business development and the commercial service delivery system. Through combined efforts, OHA and Alu Like cover many of the bases of entrepreneurship and other skills training needed to qualify Hawaiians for the loan fund program. Referrals are coordinated between both organizations providing a wide range of services.

Alu Like and the Office of Foreign Affairs on the neighbor islands also provides support to our mutual beneficiaries where opportunities for business assistance are more limited than on Oahu.

The loan fund program has its own board of directors who have approval authority over proposals forwarded to them by the loan review committee. The majority of the board are Hawaiian who are proven in various business interests and expertise and recognized bankers in Hawaii. The board of directors has established a maximum loan amount of $100,000. However, due to the large number of applicants the preferred loan size ranges from $25,000 to $50,000.

The board developed policies and procedures for the loan fund program. And it is also responsible for approval of the loans, determine action in any cases of default or late payment and generally monitor projects. All of the policies and criteria were subject to the approval of the commission of the ANA as of November 31, 1989, quarterly report, the loan fund program has received over 1,900 loan inquiries which produced 345 preapplications and a total loan request of approximately $17 million. After further screening 158 applications with a total loan value of a little over $8 million was still active.

Request for loans spanned a wide spectrum of business types including agriculture and farming, commercial fishing, construction and related activities, distributing and wholesaling, restaurant and food outlets and services in tourism, trucking, and professional fields. While 50 percent of the loan requests were from Oahu, the islands of Hawaii, Maui, Kauaii, and Molokai were also presented. Thus far 46 percent of the loan requests have been for new businesses and 54 percent have been from existing businesses. The average loan request has been a little over $50,000, and to date 26 loans have been approved in the amount of $967,000.

Specifically, descriptions of some of the more recent business projects include a native Hawaiian couple who are expanding their business from wholesaling clothing of their own design to opening their own retail outlet, the expansion of a family owned and operated existing air freight forwarding business on a neighbor island, the startup of a store selling religious books, cards and gift items, the startup of a family owned and operated music production company, the establishment of a contract sewing service for a disabled person, the expansion of a landscape contracting business on a neighbor island, funds matched by a loan from the State Department of Business and Economic Development, and a commercial lending institution for fish processing and marketing firm.

The loan fund staff continues to provide direct technical assistance or depending on the need arrange for other types of assistance from other agencies. The loan officers also receive and review monthly financial statements from each borrower and make monthly site visits to the projects. The loan fund manager is currently developing a business management class entitled "Financial Management and Control for the Small Business," which borrowers will be required to attend.

PREPARED STATEMENT

Mr. Chairman, Hawaiians are not lazy people. We have strong and viable work ethics which is being applied to Western style entrepreneurship. With encouragement and support of the Congress exciting programs such as these under discussion today will continue to be possible.

Once again, I wish to thank you and urge your continued support of Federal funding for native Hawaiians.

[The statement follows:]

Statement of Richard K. Paglinawan

Aloha, Mr. Chairman and members of the committee. I am Richard K. Paglinawan, administrator of the Office of Hawaiian Affairs [OHA], and it is my pleasure to be here today to make this presentation on behalf of OHA.

I have been asked to focus on economic development for Hawaiians, and I will do that, but first a couple of brief remarks.

Mr. Chairman, OHA has received only a few Federal grants, but each has been memorable. The grant for self-help housing from the Department of Health and Human Services, Administration for Native Americans in 1987, was matched by OHA funds and set a major precedent as the first self-help housing project to be attempted on Hawaiian homestead land. Although that particular grant has been completed, OHA continues to assist the Department of Hawaiian Home Lands, though with another funding source for self-help housing.

In 1988, I am proud to say, the U.S. Department of Education ranked OHA's substance abuse prevention education grant proposal No. 1 of 296 applicants across the country, and we received $112,725. OHA added another $35,575 of its own funds and embarked on a joint educational effort with the Castle Medical Center, the Honolulu Police Department and the State Department of Education. This project was so successful that it has been extended and expanded to a larger scale in additional counties.

Our largest Federal award to date, $3 million, has also been from the Administration for Native Americans to administer the Native Hawaiian Revolving Loan Fund [NHRLF]. These funds are being used for Hawaiian economic development through business loans to start, expand or improve businesses owned by Hawaiians who are unable to obtain loans through conventional means. You will be pleased to hear, Mr. Chairman, that every bit of the Federal grant money goes to our beneficiaries, because OHA is funding all of the administrative costs.

This project has been specifically designed to promote economic independence and self-sufficiency among Hawaiians. In addition to providing loans, project staff give technical assistance to each loan recipient to help improve their business and achieve financial success. When it is appropriate, assistance is also provided by the Bank of Hawaii, the U.S. Small Business Administration, the Chamber of Commerce of Hawaii, and the University of Hawaii Small Business Management Program. The closest agency alliance, of course, is with Alu Like.

Loans are made for a maximum of 5 years. By law, the interest rate will be 2 percent below the treasury bill rate at the time of loan approval. The business for which the loan is made must be 100 percent Hawaiian owned. Individuals, nonprofit organizations, cooperative associations, partnerships, and corporations are all eligible as long as the owners or partners are of Hawaiian ancestry.

Alu Like has identified several gap areas in Hawaiian business development and the commercial service delivery system. Through combined efforts, OHA and Alu Like cover many of the bases of entrepreneurship and other skills training needed to qualify Hawaiians for NHRLF loans. Referrals are coordinated between both organizations, providing a wide range of services. Alu Like and OHA offices on the neighbor islands also provide support to our mutual beneficiaries where opportunities for business assistance are more limited than on Oahu.

NHRLF has its own board of directors who have approval authority over proposals forwarded to them by the NHRLF loan review committee. The majority of the board are Hawaiians who are proven in various business interests and expertise, and recognized bankers in Hawaii. The board of directors has established a maximum loan among of $100,000. However, due to the large number of applicants, the preferred loan size ranges from $25,000 to $50,000.

The board developed policies and procedures for NHRLF, and is also responsible to approve all loans, determine action in any cases of default or late payment, and generally monitor projects. All of the policies and criteria were subject to the approval of the commissioner of ANA. As of the December 31, 1989 quarterly report, NHRLF had received over 1,900 loan inquiries which produced 345 preapplications and a total loan request of $17,332,074. After further screening, 158 applicants with a total loan value of $8,360,074 were still active.

Requests for loans spanned a wide spectrum of business types, including agriculture and farming, commercial fishing, construction and related activities, distributing and wholesaling, restaurant and food outlets, and services in tourism, trucking and professional fields. While 57 percent of the loan requests were from Oahu, the islands of Hawaii, Maui, Kauai and Molokai were also represented. Thus far, 46 percent of the loan requests have been for new businesses, and 54 percent have been from existing businesses. The average loan request has been for $50,240, and to date, 26 loans have been approved in the amount of $967,300.

Specifically, descriptions of some of the more recent business projects include:

A native Hawaiian couple who are expanding their business from wholesaling clothing of their own design, to opening their own retail outlet; the expansion of a family owned-and-operated existing air freight forwarding business on a neighbor island; the startup of a store selling religious books, cards and gift items; the startup of a family owned-and-operated music production company; the establishment of a contract sewing service for a disabled person; the expansion of a landscape contracting business on a neighbor island; funds matched by a loan from the State department of business and economic development and a commercial lending institution for a fish processing and marketing firm.

The NHRLF staff continues to provide direct technical assistance, or depending on the need, arrange for other types of assistance from other agencies. The loan officers also receive and review monthly financial statements from each borrower and make monthly site visits to the projects. The NHRLF manager is currently developing a business management class, entitled financial management and control for the small business, which borrowers will be required to attend.

Mr. Chairman, Hawaiians are not lazy people. They have a strong and viable work ethic which is being applied to Western style entrepreneurship. With encouragement and support of the Congress, exciting programs such as these under discussion today will continue to be possible. Once again, I wish to thank you and urge your continued support of Federal funding for native Hawaiians.

Senator INOUYE. I thank you very much, Mr. Paglinawan. And may I tell you that we are extremely proud of the work you have done for OHA and continue to do so.

You can be assured that Federal funds that you request are being seriously considered here. And I think you can count on them.

Thank you very much.

STATEMENT OF NANETTE JUDD, VICE PRESIDENT, PAPA OLA LOKAHI, STATE DEPARTMENT OF HEALTH

ACCOMPANIED BY FERN CLARK, SECRETARY-TREASURER

Senator INOUYE. We now have a special Hawaiian health panel. And we have with us the vice president of Papa Ola Lokahi, a native Hawaiian health care organization which was created by Public Law 100-579, the Native Hawaiian Health Care Act of 1988. And she is accompanied by Fern Clark, the secretary-treasurer of this organization.

Welcome.

Ms. JUDD. Thank you, Senator Inouye.

On behalf of Papa Ola Lokahi we thank you for this opportunity to testify today.

My name is Nanette Judd and with me today is Fern Clark. We are respectively vice president and secretary-treasurer of Papa Ola Lokahi, the native Hawaiian health care organization created by Public Law 100-579, the Native Hawaiian Health Care Act of 1988.

We appreciate this opportunity to share with you some of the activities we have been engaged in to date. And what we hope to achieve as our long-term objectives. With your permission we would both like to share this information with you and for the record, we would like to submit three documents to supplement our prepared testimony.

Under the act, native Hawaiians would be provided primary care, health promotion, and disease prevention services through native Hawaiian health care systems located throughout the State of Hawaii. These systems would be under the management of native Hawaiians with substantial participation by health practitioners of Hawaiian ancestry, including traditional healers.

During the first year of activities Papa Ola Lokahi is responsible for developing an overall master plan and for planning the native Hawaiian health care systems. From the second year on organizations wishing to provide services will apply for funding directly to the Federal Department of Health and Human Services [DHHS] for grants or contracts after being certified by Papa Ola Lokahi as having the qualifications and capacity to provide these services.

Papa Ola Lokahi will also be responsible for policy formulation, coordination, technical assistance, research, and evaluation. To date, we await receipt of Federal funding for our first fiscal year 1990. Fortunately for startup funds provided by our State legislature last session we have been able to commence with some strategic preliminary activities.

For example, I do want to share some of these with you. In September and October 1989 nine community informational meetings were held on Kauaii, Oahu, Molokai, Lanai, Maui, and Hawaii. In November 1989 drafts of a master plan and guidelines for planning grants to assist native Hawaiian organizations to prepare for the delivery of services in their respective native Hawaiian communities were completed and distributed.

We have concluded that we cannot plan for these community based health care systems without simultaneously developing community based native Hawaiian organizations that are capable of providing such services. Therefore we have decided that most of our planning funds will be to develop such organizations and support the operational planning.

We have been encouraging the formation of single planning committees on each island to facilitate cooperative efforts, to ensure that no group of native Hawaiians is left unserved and to minimize administrative cost.

Up to the present we have been able to conduct all of these activities with State funding. As you know Congress appropriated $800,000 out of the authorized $2.6 million for fiscal year 1990. We are currently in negotiations with DHHS for receipt of these funds and, we will be receiving $782,000 instead of $800,000, because of mandated sequestration and 1-percent set-aside for evaluation.

Of this amount $684,000 is for planning and $98,000 is for the administrative costs of Papa Ola Lokahi.

Senator, although it will be difficult, we at Papa Ola Lokahi believe that we can accomplish our planning mission with this level of funding. However, we are most concerned regarding the uncertainty of future funding; $5 million is authorized in fiscal year 1991 for services delivery, rising to $10 million in fiscal year 1992.

We do need as much of these authorized funds as the Congress can reasonably provide, because there are over 200,000 native Hawaiians residing on seven separate islands and many of them live in rural settings, which creates unique access and resource problems which are associated with rural areas; $1 million is also authorized at each fiscal year for Papa Ola Lokahi to implement and update the master plan, support training as needed to staff these systems, and to conduct research in diseases that are most prevalent among native Hawaiians.

We received only $98,000 out of the possible $1 million in this fiscal year, which will certainly impede our progress to fulfill all of these responsibilities, particularly, if funding continues at this level. Of added concern is the extended lapse time which occurs between authorization and actual receipt of the appropriations in each fiscal year.

Although native Hawaiians from the State of Hawaii respond with gratitude and commitment to the intent, purpose, and financial resources of the Native Hawaiian Health Care Act, the transitory nature of Federal funding creates uncertainty and obvious planning obstacles.

We understand the reasons for these delays, however, planning and performing against a background of such fiscal uncertainties as to the amount of funds, when they will become available, and the prospects for future reauthorization and funding of the Public Law 100-579 beyond fiscal year 1992 presents many barriers to progress.

Papa Ola Lokahi and the native Hawaiian communities realize, however, that we have been given a rare opportunity to develop and design primary health care, health promotion, and disease prevention services for a population which has been defined at extreme health risk. The State of Hawaii with its rich history and unique geography and demographics presents an untapped setting for such an overture to take place.

PREPARED STATEMENT

The challenge before us is not only to prove that this effort is appropriate and cost effective, but most importantly that it needs to be executed with sensitivity and appreciation for the strengths of the culture at focus. The consequence we anticipate will be an integrative approach of Western and traditional health care practices into a health care delivery system for native Hawaiians.

And I thank you once again for this opportunity to present this testimony and for your continuing effort Senator, to support our efforts.

Thank you.

[The statement follows:]

STATEMENT OF NANETTE KAPULANI JUDD

My name is Nanette Kapulani Judd, Vice-President of Papa Ola Lōkahi, the Native Hawaiian health care organization created by Public Law 100-579, the Native Hawaiian Health Care Act of 1988. With me today is Fern Iwalani Clark, Secretary-Treasurer of Papa Ola Lōkahi. We thank you for the opportunity to inform you of what has happened since the Act was enacted in October 1988; what we hope to accomplish in the next year; and the long-term objectives we hope to achieve.

Under the Act, Native Hawaiians, or persons of Hawaiian ancestry, will be provided primary care, health promotion, and disease prevention services through Native Hawaiian health care systems distributed throughout the State of Hawai'i. These prevention-oriented services will supplement existing health and medical services. Nine (9) such systems are authorized, up to two on each of the islands of Kaua'i (which shall also serve Ni'ihau), O'ahu, Maui, and Hawai'i, and one on Moloka'i (which shall also serve Lana'i). These systems will be under the management of Native Hawaiians, and with substantial participation by health practitioners of Hawaiian ancestry, including traditional healers.

Five organizations are represented on the Board of Papa Ola Lōkahi: 1) Alu Like, Inc., a private, nonprofit, Native Hawaiian service and training organization; 2) E Ola Mau, a private nonprofit organization of Native Hawaiian health professionals; 3) the Office of Hawaiian Affairs of the State of Hawai'i; 4) the Office of Hawaiian Health, Department of Health, State of Hawai'i; and 5) the University of Hawai'i. All of the Board members are Native Hawaiians. I, Nanette Judd, am president of E Ola Mau and its representative on Papa Ola Lōkahi. Fern Clark is Administrator of the Office of Hawaiian Health and represents the Department of Health. Our president, Myron Thompson, represents Alu Like, Inc., and is one of its founding members. Thomas Kaulukukui represents the Office of Hawaiian Affairs and is Chair of its Board of

Directors. Gladys Ainoa Brandt represents the University of Hawai'i, having served four terms as Chair of its Board of Regents.

During the first year of activities under Public Law 100-579, Papa Ola Lōkahi is responsible for developing an overall Master Plan, and for planning the Native Hawaiian health care systems. From the second year on, organizations wishing to provide services will apply directly to the federal Department of Health and Human Services (DHHS) for grants or contracts. These organizations must be certified by Papa Ola Lōkahi as having the qualifications and capacity to provide the services and meet the requirements under the grants or contracts with DHHS. Papa Ola Lōkahi will also be responsible for coordination, implementation, and updating of the master plan, supporting training as needed of Native Hawaiian health care practitioners, community outreach workers, counselors, and cultural educators; and identification of and research into the diseases that are most prevalent among Native Hawaiians, including behavioral, biomedical, epidemiological, and health services. Thus, the Native Hawaiian health care systems will be responsible for providing primary care, health promotion, and disease prevention services to Native Hawaiians in their service areas. Papa Ola Lōkahi is responsible for policy formulation and coordination, technical assistance, research, and evaluation, and will work with the community-based health care systems to coordinate their individual efforts into a statewide system of preventive health services for Native Hawaiians.

Activities To-Date

Because the Act was enacted in October 1988 and federal fiscal year 1989 had already commenced, the first fiscal year that federal appropriations could be available was 1990, which began in October 1989. To date, we have yet to receive any federal funding, for the reasons explained below. Fortunately, however, we have been able to initiate our activities with start-up funds provided by the

Hawai'i State Legislature. Let me mention some of our activities to date.

In February 1989, Papa Ola Lōkahi was incorporated and the Board of Directors was designated by the five parent organizations. The Board then formulated and adopted a Program Description, which states its mission and its goals and objectives.

The State Legislature provided startup funds for Papa Ola Lōkahi, which became available on July 1, 1989, the start of the State's 1990 fiscal year. Earlier, State funds had been provided to E Ola Mau, one of the parent organizations of Papa Ola Lōkahi, to initiate activities in the period before Papa Ola Lōkahi could begin operations. These E Ola Mau activities included informing Native Hawaiians of the legislation, identifying traditional healers, and initiating organizational efforts among Native Hawaiian organizations and communities.

Papa Ola Lōkahi began operations on July 1, 1989, under its Executive Director, Dr. Lawrence Miike, who is also Professor of Medical Policy at the School of Medicine, University of Hawai'i -- Manoa, and previously Senior Associate at the Office of Technology Assessment, United States Congress.

Papa Ola Lōkahi has engaged in the following activities to date:

We have hired an analyst experienced with existing data systems in Hawai'i. We have commenced to identify and compile information related to the health status and demographic characteristics of Native Hawaiians and the other ethnic groups residing in Hawai'i. We are compiling information on health and medical services currently available or potentially available to Native Hawaiians and other residents of Hawai'i.

In September and October 1989, with the assistance of Alu Like, Inc., the Office of Hawaiian Affairs, and E Ola Mau, we held nine community meetings on Kaua'i, O'ahu, Moloka'i, Lana'i, Maui, and Hawai'i, to explain the provisions of the Native Hawaiian Health Care Act and present some of the statistics we had compiled.

In November, we joined with The National Cancer Institute, Division of Cancer Prevention and Control, Special Populations Studies Branch, in its sponsorship of twelve informational meetings throughout the islands to give focus to and facilitate the establishment of a cancer prevention and control research network for Native Hawaiians. These meetings included presentations by National Cancer Institute staff, the Director of the Cancer Research Center of Hawai'i, and two traditional Native Hawaiian healers.

In October and November we collaborated with the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDKD) on a report which will be delivered by NIDDKD to Congress in early 1990 on diabetes among Native Hawaiians residing in Hawai'i.

We have established a research committee of persons conducting or interested in research on Native Hawaiian issues. Two meetings have already been held, the most recent in February 1990, where we addressed community concerns and input into research conducted in Native Hawaiian communities.

In late November, we completed and distributed throughout the State, over 200 copies of drafts for review and comment of: 1) the activities that must be undertaken to develop and implement a Master Plan, and 2) guidelines for planning grants to community-based Native Hawaiian organizations in order to help them prepare for the delivery of services in their respective Native Hawaiian communities.

Because preventive services under Public Law 100-579 are supplemental to existing health and medical care services, a Master Plan must be directed at the following objectives: 1) assessing the health status and health care needs of Native Hawaiians living in Hawai'i; 2) planning and establishing the resources and services that are authorized under the Native Hawaiian Health Care Act; 3) identifying and evaluating all other current and planned health resources and services for Native Hawaiians or for which Native Hawaiians will be eligible; 4) coordinating these various resources and services; and 5) developing monitoring and evaluation systems in order to improve and create health resources and services and to measure progress toward improving the health of Native Hawaiians.

The purpose of the Master Plan is twofold. First, it identifies the activities and resources that will be necessary to elevate the health of Native Hawaiians to the highest level possible, including resources and services not directly provided through the Native Hawaiian Health Care Act; to modify Hawai'i's health care system to more effectively enable participation by, address the needs of, and serve Native Hawaians; and to create structures within Hawai'i's health care system that will continue to effectively address the health needs of Native Hawaiians. Second, the Master Plan provides reference points against which progress toward these goals can be measured.

Papa Ola Lōkahi, as previously mentioned, has the responsibility to plan and authorize up to nine (9) Native Hawaiian health care systems throughout the State. Once recognized and certified by Papa Ola Lōkahi, organizations intending to provide the primary care, health promotion, and disease prevention services authorized by the Act will apply directly to the federal DHHS with their proposals. In the initial planning year of Public Law 100-579, the goal of Papa Ola Lōkahi is to prepare Native Hawaiian communities and develop their organizational capacity to provide the required services. We have concluded that we cannot plan for the community-based health care systems without simultaneously developing community-based Native Hawaiian organizations that are capable of providing such services. Therefore, most of our planning funds will be used to develop community-based Native Hawaiian organizations and to support their operational planning. Each community-based organization will be responsible for planning their specific health care system. Papa Ola Lōkahi will assist and coordinate planning for functions that all health care systems will share, such as fiscal and patient-monitoring systems, matching funds requirements, and sliding fee scales.

Continuing Efforts

Up to the present, we have conducted all activities with State funding. As you know, Congress has appropriated $800,000 out of an authorized level of $2.6 million for fiscal year 1990. These federal appropriations have been delayed because of the usual administrative delays as well as President Bush's veto of the original appropriations legislation that contained funding for the Native Hawaiian Health Care Act.

We are currently in negotiations with DHHS for receipt of these funds and will be receiving $782,000 instead of $800,000 because of mandated sequestration and one percent set-aside for evaluation. Of this amount, $684,000 (compared with the authorized level of $1.6 million) will be for planning and $98,000 (compared with the authorized level of $1 million) will be for administrative support.

As previously described, up to nine (9) health care systems are authorized, two each on Kaua'i (which shall also serve Ni'ihau), O'ahu, Maui, and Hawai'i, and one on Moloka'i (which shall also serve Lana'i). Of the planning funds, we have allocated $50,000 for each possible system, or $100,000 each for Kaua'i, O'ahu, Maui, and Hawai'i, and $50,000 for Moloka'i, for a total of $450,000. We will also keep available between $100,000 to $150,000 in a reserve fund for islands that have additional planning needs. The remaining $84,000 to $134,000 will be utilized for statewide planning activities (e.g., how to coordinate non-Native Hawaiian services with the Native Hawaiian services, developing referral services to medical specialty and hospital care, etc.) and for technical assistance (e.g., uniform accounting systems, patient-tracking systems, technical assistance workshops, etc.).

The formation of island-wide planning committees on each of the islands has been encouraged, even though Kaua'i, O'ahu, Maui, and Hawai'i are authorized to develop two rather than one health care system. The reason for island-wide planning is to encourage cooperative efforts, ensure that no group of Native Hawaiians are left unserved, and minimize administrative costs. Each island could develop a single administering organization, with services provided through one or two service systems. For example, Kaua'i is moving toward a single administering organization, with services provided through west Kaua'i and east Kaua'i bases. Hawai'i may develop a similar organizational approach, while O'ahu may develop a rural system and an urban system.

In spite of the reduced funds which have been made available to us for administration and planning, we are challenged to persevere in our mission. Our success is greatly dependent on the future funding which is received for services delivery by the community-based organizations and for the support and resource-building functions for Papa Ola Lōkahi. Five million dollars are authorized in fiscal year 1991 for services delivery, rising to $10 million in FY 1992. We need as much of these authorized amounts as the Congress can reasonably provide, as there are over 200,000 Native Hawaiians residing on seven islands, and many of them live in rural settings which create unique access and resource problems.

One million dollars in each fiscal year is authorized for Papa Ola Lōkahi to coordinate, implement, and update the Master Plan; to support the training of persons needed to staff the systems; and to identify, conduct research in, and intervene when possible in diseases that are most prevalent among Native Hawaiians. We received only $98,000 out of a possible $1 million in this fiscal year, which will certainly impede our progress to fulfill all of our responsibilities, if funding continues at this level.

Long-term Objectives

Although Native Hawaiians from the State of Hawai'i respond with gratitude and commitment to the intent, purpose, and financial resources of the Native Hawaiian Health Care Act, the transitory nature of federal funding creates uncertainty and obvious planning obstacles. Although we understand the reasons for delays for receipt of federal funds, planning and performing against a background of such fiscal uncertainties as the amount of funds, when they will become available, and the prospects for future reauthorization and funding of Public Law 100-579 beyond fiscal year 1992, presents many barriers to progress.

Papa Ola Lōkahi and the Native Hawaiian communities realize, however, that we have been given a rare opportunity to develop and design primary health care, health promotion, and disease prevention services for a population which has been defined to be at extreme health risk. The State of Hawai'i and its rich history and unusual geography and demographics present an untapped setting for such an overture to take place.

The challenge before us is not only to prove that this effort is appropriate and cost-effective, but most importantly, that it needs to be executed with sensitivity and appreciation for the strengths of the culture at focus. The consequence, we anticipate, will be an integrative approach of western and traditional health care practices into a health care delivery system for Native Hawaiians.

Senator INOUYE. I thank you very much, Ms. Judd and Ms. Clark.

As you know this Hawaiian health program was an initiative on the part of the Congress and was not part of the administration's initiative. Oftentimes when a program is not initiated by the administration, there happens to be bureaucratic slowdowns, possibly because they were not prepared for this program. But I have been assured that funds will be forthcoming expeditiously.

And I can further assure you that my colleagues on this committee will be looking favorably upon increased funding for this present fiscal year. We do not want this program to fail. It is an initiative that is being watched and monitored by other native Hawaiian groups and naturally, I will do my best to see that it succeeds.

Thank you very much.

STATEMENT OF CHRISTIAN GULBRANDSEN, DEAN, SCHOOL OF MEDICINE, UNIVERSITY OF HAWAII

ACCOMPANIED BY:

PATRICIA EWALT, DEAN, SCHOOL OF SOCIAL WORK

JERROLD MICHAELS, DEAN, SCHOOL OF PUBLIC HEALTH

Senator **Inouye**. We now have a special panel for the Pacific Basin. May I call upon the dean of the University of Hawaii School of Medicine, Dr. Chris Gulbrandsen; the dean of the University of Hawaii School of Social Work, Dr. Patricia Ewalt; the dean of the University of Hawaii School of Public Health, Dr. Jerry Michaels; trustee of the estate of James Campbell, and chairman of the Governors Pacific Health Promotion and Development Center, the Honorable Fred Trotter.

Dr. Gulbrandsen.

Dr. **Gulbrandsen**. Mr. Chairman, members of the committee, I appreciate the opportunity to testify this morning. This testimony concerns the continuation and further development of a strategy to address the specific health manpower needs in the Pacific Basin.

For more than two decades the University of Hawaii has been working with the Pacific Basin countries to address issues related to health delivery through the development of health manpower. First, through the training of physician's assistants, second, the development of rehabilitation technicians, and third and most recently, the initiation of a Pacific Basin medical officers training program.

Today the medical officers training program is in place with students from Micronesia and American Samoa. The first 16 students will graduate as medical officers in 1991. These graduates will function as primary care physicians. As the next generation of indigenous health leaders, they will develop and implement health care systems that are appropriate and responsive to the real needs of the region.

In 1989, the Western Pacific regional office of the World Health Organization declared the Pacific Basin medical officers training program a significant educational institution in the Pacific.

The development of the training program is a part of an overall strategy of the University of Hawaii to address the health manpower shortage in Micronesia. It is going well and enjoys the support of the countries in the Pacific. Now we are prepared to address the larger health manpower issues through legislation such as Senate bill 1606. Included in the bill are additional manpower development projects such as the establishment of nurse training programs and other health professional training initiatives.

These training efforts will be targeted toward ensuring that residents of the Pacific Basin will be capable of attending and graduating from recognized health professional programs in medicine, dentistry, nursing, optometry, pharmacy, podiatry, public health, psychology, and allied health. Provisions are included for continuing medical education, which would support the upgrading of health professional, within the Pacific Basin and would support residency training and primary care and preventive medicine for the National Health Service Corps officers assigned to the region.

The upgrading of currently employed Pacific island health personnel will involve management and social services training. In addition, continuing technical training will be initiated for new health workers such as environmental sanitation aids, social work assistants, community and hospital nurse assistants, and allied health technicians.

Finally, appropriate health promotion and disease prevention efforts in public health will be established with the citizens of the Pacific Basin.

PREPARED STATEMENT

The State of Hawaii, more specifically, the University of Hawaii is committed to providing the leadership in the development of health manpower in the Pacific Basin. But Hawaii is unable to undertake the financial requirements which are needed to pursue the initiatives. It is likely that if Hawaii does not pursue this commitment with the help of the Federal Government, health manpower development programs in the Pacific will not develop.

The support of this subcommittee has been vital and sincerely appreciated by those of us committed to health manpower development in the Pacific Basin.

Thank you for the opportunity to testify this morning.

[The statement follows:]

STATEMENT OF CHRISTIAN GULBRANDSEN

I am Christian Gulbrandsen, dean of the John A. Burns School of Medicine. This testimony concerns the continuation and development of a strategy to address the health manpower needs of the Pacific Basin.

For more than two decades, the University of Hawaii School of Medicine has been working with the Pacific Basin countries to address issues related to health delivery through the development of health manpower: first, through the training of physician assistants (Medex); second, the development of rehabilitation technicians; and, third and most recently, since 1986, the initiation of a Pacific Basin Medical Officers Training Program (PBMOTP).

Today, the Medical Officers Training Program is in place with students from Micronesia and American Samoa. The first 16 students will graduate as medical officers in 1991. These graduates will function as primary care physicians. As the next generation of indigenous health leaders, they will develop and implement health care systems that are appropriate and responsive to the real needs of the region.

Because of the unusual characteristics of the students, there are features of the Medical Officers Training Program which call upon innovated and practical approaches. For example, the first year students are exposed to an intensive "survival course" in English as a Second Language (ESL) since all students come from a multiplicity of languages. This course has a significant impact on study skills and the ease with which the students progress through the Program. In addition, all students and faculty receive a "crash course" in the Pohnpeian language delivered by a former Peace Corps language facilitator. This has eased the need for interpreters in the clinics and hospital where local patients are treated by the students and faculty. The curriculum is a community-oriented problem-and-competency-based approach designed for students with disadvantaged educational backgrounds. The curriculum is practical and appropriate to regional resources. Appropriate basic sciences are integrated from the outset into the clinical and public health training. Emphasis is given to those preventive and curative skills which are critical in the Pacific Basin.

In 1989, the Western Pacific Regional Office of the World Health Organization declared the Pacific Basin Medical Officers Training Program a "significant educational institution" in the Pacific.

The development of the training program is a part of overall strategy of the University of Hawaii to address the health manpower shortage in Micronesia. It is going well and enjoys the support of the countries in the Pacific. Now, we are prepared to address the larger health manpower issues, through legislation such as S.B.

1606 where top priority is given to the continuation of the Pacific Basin Medical Officers Training Program on Pohnpei. Included in the Bill are additional manpower development projects such as the establishment of nurse training programs and other health professional training initiatives which include scholarships. These training efforts will be targeted towards ensuring that residents of the Pacific Basin will be capable of attending and graduating from recognized health professional programs in medicine, dentistry, nursing, optometry, pharmacy, podiatry, public health, psychology, and allied health. Provisions are included for continuing medical education which would support the upgrading of the health professional within the Pacific Basin as well as the residency training in primary care and preventive medicine for the National Health Service Corps Officers assigned to the region. The upgrading of currently employed Pacific Island health personnel will involve management and social services training. In addition, continuing technical training will be initiated for new health workers such as environmental sanitation aides, social work assistants, community and hospital nurse assistants, and allied health technicians. Finally, appropriate health promotion and disease prevention efforts in public health will be established with the citizens of the Pacific Basin.

To mobilize the above activities, the young men and women of the Pacific Basin must be counseled and inspired to enter the health professions. It is proposed that a "Unified Health Training Program" such as that envisioned for Hawaii be implemented. This program is designed to recruit and select trainees for health care careers. In such a program, students with a high school diploma who desire training in the health care fields will be enrolled in a program which involve paid hospital work such as an orderly, an aide, a ward clerk, a lab assistant, or an x-ray technician's assistant. At the same time that the students are working, they will be trained in clinical sciences and will be educated in the humanities. The clinical training will teach them the basic sciences and clinical skills necessary to perform the next more sophisticated task required in a health care field. This training will be problem-based and evaluated using competency-based tools, and the students will proceed at their own pace. They may branch off into more intensive training in any of the health care fields should they desire and be capable, and they may challenge certifying examinations in the various health care fields after satisfying the competency-based evaluation. Education in the humanities will emphasize reading, writing, speaking, history, economics, and their role in society.

Such a program will recruit heretofore untapped group of people into health care careers. High school students from all socioeconomic levels will apply for enrollment for a variety of reasons ranging from needing a job to interest in the health care fields as a career. Once in the program or while working in the hospital in a job side-by-side with students in the program, workers will become aware of opportunities, talents, and interests which they may never have otherwise realized. Students and workers currently involved in certain areas of health care will become aware of opportunities and follow their interests and abilities into further training. This program will select and self select people to various fields within the health care area according to their abilities, desires, and motivations. It will permit identification of people who care about caring for the sick and disabled. It will pay students as they learn, thereby attracting students from low economic strata and keeping them from getting into financial debt. It will allow students who must stop training for personal reasons to continue to work, make a living without being lost to the health care industry and, later, resume training. This program will permit the various health care workers to know the tasks and roles of health care workers in different fields, thereby increasing mutual respect, decreasing fragmentation of health care delivery, and improving service to the sick. Finally, the program will help alleviate the health manpower shortage by increasing the number of health care trainees and trainers delivering care in the system.

The State of Hawaii, more specifically, the University of Hawaii, is committed to providing the leadership in the development of health manpower in the Pacific Basin. But, Hawaii is unable to undertake the financial requirements which are needed to pursue the initiatives. It is also obvious that if Hawaii does not pursue this commitment with the help of the Federal government, health manpower development programs in the Pacific may not develop.

The support of this Subcommittee has been vital and sincerely appreciated by those of us from the University of Hawaii and by the Micronesian and Samoan leaderships.

Thank you for the opportunity to testify this morning.

Senator INOUYE. Thank you very much, Dean.

STATEMENT OF PATRICIA EWALT

Senator INOUYE. And may I now call on the dean of the University of Hawaii, School of Social Work, Dr. Ewalt.

Ms. EWALT. Mr. Chairman, and members of the committee, I thank you for this opportunity to testify on behalf of the University of Hawaii, School of Social Work, as well as the 126,000 nationwide membership of the National Association of Social Workers.

Senator Inouye, first, I wish to thank you for your constant recognition and support for the quality of care provided by clinical social workers in health and mental health settings. We are particularly grateful also for your leadership in making Indian health profession scholarships available to American Indians attending graduate schools of social work, as well as your continued efforts to recognize graduate programs in social work as health professions through title 7 of the Public Health Service Act.

Today the expectations of families are probably higher than they have ever been before. With families expected to take care not only of children, but their older members and members with sickness and disabilities. All of this has to be done usually with both parents working, or when there is only a single working parent in the household. The burden falls even more heavily on disadvantaged families who have even fewer resources.

The specific purposes of social work are to organize social programs and clinical services that enable families to function at their very best. Within this general emphasis the profession has an explicit commitment to disadvantaged populations. Therefore, social work is specifically suited to achieve public policy goals for strengthening families and in particular disadvantaged and underserved populations.

For this reason, it is imperative to recruit and train a sufficient number of social workers and in particular essential to recruit students who are themselves from minority and disadvantaged populations. Our school, the University of Hawaii School of Social Work provides an example of the benefits to be gained by training funds for disadvantaged minority students.

Our particular focus in minority training is on minorities of the Pacific, and in particular, native Hawaiians, Filipinos, Samoans, and others of Pacific ancestry. Since 1973 the National Institute of Mental Health has awarded funds to the school to retain minority students including residents of Hawaii and of the U.S.-related Pacific islands. About 250 underrepresented minority students have graduated from our MSW program, thanks to these grants. About 65 have received stipends and almost 200 other students have received services which helped them complete their studies.

The legislature of our State has recognized this program and is continuing its own additional stipend program each year with permanent funding. A second type of NIMH grant awarded to us this past year is the minority access to research of MARK grant. In this project we are helping minority students in social work, nursing and psychology to begin careers in mental health research while they are still undergraduates.

Third, we intend to expand on the concept of the underrepresented minority recruitment program by developing onsite training in

American Samoa. This effort could be greatly enhanced by title 3 of Senate 1606, the Minority Health Improvement Act.

As a final example, we are preparing a proposal to implement the interdisciplinary rural health training initiative of the health resources and services administration to prepare health care workers to meet the needs of native Hawaiians and other minorities on each of the islands of our State.

Funding for social work, clinical, and research training must be enhanced if a sufficient number of social workers are to be trained to address the needs of minorities and rural areas. Specific needs are as follows: First, we applaud Senate 1606, the Disadvantaged Minority Health Improvement Act, title 3 establishing the Pacific Basin Health Services Council. Together with the other schools in our college of health sciences, we will be able to conduct activities in the Pacific in ways that would not otherwise have been possible.

We note, however, a serious deficit entitled to regarding disadvantaged minorities in the health professions. Although nine types of professional schools and graduate programs are included, social work is omitted.

Social work continues to be an unrepresented profession in title 7 of the U.S. Public Health Service Act. And as long as this is so, there will be an insufficient number of social workers trained to meet the needs of disadvantaged people. We strongly urge you to modify the underlying policy in order to ensure that sufficient funds are regularly provided for social work in the health professions account.

Second, NIMH clinical training funds which are distributed to the five mental health professions have been drastically reduced over the years. We recommend funding at least at the $26 million projected level. This would at least be a step in the right direction.

For similar reasons we urge funding of the rural health care grants at the $5 million authorization level and also an increase in the National Health Service Corps to expand services of social workers, nurses, and physicians in underserved areas.

I call your attention, however, to an area that has not yet received the attention that it deserves and that has a great deal of promise. There is currently—as you know, Senator—a severe shortage nationally of child protective service workers and of creative approaches to child welfare services generally.

There are many persons serving in the child welfare system who do not have the advantage of professional social work education and yet who are called social workers. Yet there is scant Federal support for child welfare training and no established tradition of doctoral research support in that area.

Doctoral research funding is an excellent investment in the future since researchers often continue to study and teach future students in the area in which they began as doctoral students. We, therefore, urge funding for masters level training and for doctoral research support in any newly proposed child welfare legislation.

PREPARED STATEMENT

Finally, we recommend establishment of a social work research center comparable to the National Center for Nursing Research.

There is currently a task force on social work research funded by the National Institute of Mental Health. I would encourage the committee to request a report of this task force early in 1991 and to consider its recommendations in support of social work research.

We believe that strengthening social work training and research programs is an important step in strengthening the mental, physical and emotions health of this country's families. Your interest in these matters and this opportunity to testify is greatly appreciated. Thank you.

[The statement follows:]

STATEMENT OF PATRICIA L. EWALT, PH.D.

Mr. Chairman and Members of the Committee:

Thank you for this opportunity to testify on behalf of the University of Hawaii School of Social Work as well as the 126,000 nation wide membership of the National Association of Social Workers.

Senator Inouye, first I wish to thank you for your constant recognition and support for the quality of care provided by clinical social workers in health and mental health settings. I am particularly grateful for your leadership in making Indian Health Professions Scholarships available to American Indians attending schools of social work, as well as your continued efforts to recognize graduate programs in social work as health professions schools through Title VII of the Public Health Service Act.

Today the expectations of families are probably higher than ever before with each family expected to take care not only of its children but also of its older members and members with sickness and disabilities. All of this is to be done even though both parents are working or there is only a single working parent to bear the full responsibility. The burden falls even more heavily on disadvantaged families who have even fewer resources available to them.

The specific purposes of social work are to organize social programs and provide clinical services that enable families, and other individuals, to function at their best. Within this general emphasis the profession has an explicit commitment to educate practitioners for work with disadvantaged populations. Therefore social work is specifically suited to achieve public policy goals for strengthening families and, in particular, disadvantaged and underserved populations.

For this reason, it is imperative to recruit and train a sufficient number of social workers to address social service needs. In particular, it is essential to recruit students who are themselves from minority and other disadvantaged populations.

Our school, the University of Hawaii School of Social Work, provides an example of the benefits produced by training funds for disadvantaged minority students. Our particular focus in minority training is on minorities of the Pacific. Thus the focus is on Native Hawaiians, Filipinos, Samoans and others of Pacific ancestry.

Since 1973, the National Institute of Mental Health has awarded funds to our school for a special program to recruit and retain minority students including residents of Hawaii and of the U.S. related Pacific islands. About 250 underrepresented minority students have graduated from our MSW program thanks to these grants. About 65 have received stipends and almost two hundred other students have received services which helped them complete their studies. Unfortunately no funds were awarded to us this year but we hope the award will be resumed in future.

A second type of NIMH grant, awarded to us this past year, is the Minority Access to Research or MARC grant. In this project we are helping minority students in social work, nursing and psychology to begin careers in mental health research while they are still undergraduates.

Thirdly, we are seeking to expand on the concept of underrepresented minority recruitment programs on our own campus by working with earlier graduates to develop on-site training in American Samoa. This effort could be greatly enhanced by Title III of Senate 1606, the Minority Health Improvement Act.

As a final example, we are also preparing a proposal to implement the interdisciplinary rural health training initiative of the Health Resources and Services Administration. Through this initiative, health care workers will be better trained to meet the needs of Native Hawaiians and other minorities on each of the islands of our state.

Funding for social work clinical and research training must be enhanced if a sufficient number of social workers are to be prepared to address the health care needs of minorities and rural areas and other public policy initiatives. Specific training needs are as follows:

First, we applaud Senate 1606, the Disadvantaged Minority Health Improvement Act of 1989. Title III, establishing a Pacific Basin Health Services Council, will allow the University of Hawaii College of Health Sciences including the School of Social Work to increase its assistance for training in the Pacific Trust Territories. Through this means we expect to be able to expand current activities in the Pacific in ways that would otherwise be impossible.

We note, however, a serious deficit in Title II regarding Disadvantaged Minorities in Health Professions. Though nine types of professional schools and graduate programs are included, social work is omitted. Social work continues to be an unrepresented profession in Title VII of the U.S. Public Health Service Act and as long as this is so, there will be an insufficient number of social workers trained to meet the needs of disadvantaged people. We strongly urge you to modify the underlying policy in order to ensure that sufficient funds are regularly provided for social work in the health professions account.

NIMH Clinical Training funds, which are distributed to five mental health professions, have been drastically reduced over the years. For social workers to be trained for work in underserved areas and with underserved populations such as people with severe, persistent mental illness, children, the elderly, homeless and rural people, we recommend funding at least at the $26 million level. This would be a step in the right direction.

For similar reasons, funding Rural Health Care Grants, which provide funds to programs that offer interdisciplinary training in the health professions, at the $5 million dollar authorization level is important as well as an increase in the National Health Service Corps to expand service of social workers, nurses, and physicians in underserved areas.

I call to your attention, however, an area that has not yet received the attention that it deserves and that has a great deal of promise. There is currently a severe shortage nationally of child protective service workers and of creative approaches to child welfare services generally. As you know, we see many problems in the child welfare system because people who serve as social workers have not in fact received professional social work education. Yet there is scant federal support for child welfare training and no established tradition of doctoral research support in that area.

Doctoral research funding is an excellent investment in the future since researchers often continue to study and teach future students in the area in which they began as doctoral students. We strongly encourage that funding for master's level training and doctoral research support be included in newly proposed child welfare legislation.

Finally, we recommend additional support be given to social work research more generally. Establishment of a Social Work Research Center comparable to the National Center for Nursing Research should be considered. In this connection, there currently exists a Task Force on Social Work Research broadly representative of the research capabilities of the profession and funded by the National Institute of Mental Health. I encourage your committee to request a report of this Task Force in early 1991 and to consider its recommendations in support of social work research.

We believe that strengthening social work training and research programs is an important step in strengthening the mental, physical and emotional health of this country's families.

Your interest in these matters and this opportunity to testify are greatly appreciated.

Senator INOUYE. I thank you very much, Dean.

I can assure you that your words will be very seriously considered by this committee.

STATEMENT OF JERROLD MICHAELS

Senator INOUYE. Next I am pleased to call upon a friend, the dean of the University of Hawaii, School of Public Health, Dr. Jerry Michaels.

Dr. Michaels.

Dr. MICHAELS. Senator, my testimony is to be on the Pacific Basin. But I was moved during Senator McCain's testimony to remember a conversation that we had some 25 years ago when I was serving as Assistant Surgeon General of the U.S. Public Health Service. At the time holding a leadership responsibility for that service for the American Indians and reviewed with you the abominable health conditions and statistics. And you indicate that you wanted to help.

The changes that have taken place over that quarter of a century are hallmarks of public health accomplishment globally. And while still there is a good deal remaining that needs to be done, I wanted to bring to the attention of this group, and to you, sir, that this progress would not have been possible had it not been for your personal intervention.

I am testifying today on what I believe is one of the most unique—and certainly for me one of the most rewarding collaborative activities that I have ever been involved in, in my 40 years in the field of public health. That unique opportunity is the State of Hawaii's Governors Pacific Health Promotion and Development Center.

It is unique and it is historic, because it represents a partnership of governments of the Pacific nations with the government of the State of Hawaii, the Federal Government of the United States, the private sector of health and medicine in Hawaii and the Pacific Basin and the University of Hawaii.

The earliest strategic action on that as I recall was in 1983, when you called together a group of people from the Public Health Service, the Assistant Secretary of Health, Assistant Surgeon General, San Francisco, region 9, a number of other Public Health Service and congressional aids. And what followed was the first thoroughgoing survey of health conditions and services in the Pacific, particularly, the U.S.-related nations of the Pacific. And that was conducted by the University of Hawaii in 1984.

A second significant step in the center concept having now a base line of what health conditions truly were and to have a sense of the urgency was the creation of the center itself by Governor Waihee.

Now he did that in the first month of his tenure in office as Governor and the establishment of that center, which has become an operating entity now and has coalesced major health and health-related resources in Hawaii and in the Pacific in the extremely wholesome effort that not only contributes to the health status of people in the Pacific or their enhancement of health status, but we believe simultaneously to assist Hawaii in its own health care development. And in particular providing guidelines for health care for native Americans in Hawaii.

Linked closely with this effort is the Pacific Island Health Officers Association and the Public Health Service. This coalition has been able to carry out some remarkable things. And my submitted testimony will make record of that, Senator.

During the first 2 years of operation the secretariat for the management of that center was lodged with the State health department and with the school of public health of the University of Hawaii. The Governor some years ago, recognizing the need to have that center more nearly and closely related to the private sector which is providing many of the resources, established its new locus in the Rehabilitation Hospital of the Pacific, and it was so selected because that was a center that for a number of years was very active in the Pacific and because the people in the Pacific held confidence—and still hold confidence—in what that center has done.

Now your continued support of this activity permitted us to resurvey the conditions in the Pacific in 1989. And again, it is not my purpose here to provide the details of that since it is still in draft form. But it seemed to me it would be appropriate to bring to your attention, Senator, five areas of concern and interest to which we will address ourselves too.

And I might say that the difference between 1984 and 1985 show some overall measurable progress but still reflecting a low level of adequacy—and as we would measure it in the United States—not at all acceptable. Whatever improvements we have I think are attributable to internal resourcefulness on the part of the people of the Pacific and in large part to external support received from the Federal Government—and again, Senator Inouye, you very well know that without your personal significant strong and knowing emphasis that would not have been possible.

It is also possible in part because of some dedicated people in the Federal Government who have assisted us. And one of those individuals, Claudia Bakey, is in the audience today from the National Cancer Institute.

The five areas, Senator, where major improvement is going to be necessary are as follows. First, in leadership. There is a health leadership crisis in the Pacific. Senior health leaders are retiring, few persons with expertise are available to take their jobs. We are counting on the school of medicine's efforts in that regard and the medical officer school to be of assistance.

Manpower development and training—major shortages exist and there is a need to develop a consistent and supportive plan. Third, health systems planning and development—none of the jurisdictions are pursuing deliberate development of their health systems through the process of planning. An additional effort here is absolutely imperative.

The rapid population growth is the fourth area. And that is one that is classic of developing nations in Asia. The relevance is true also in the Pacific. The rapid population growth, changing demography of people who are there create additional problems of significant dimension.

And finally, while improvements have been made in clinical services in the frank conditions that present themselves in the hospitals there is, what I would call, an overall public health neglect in the most critical area—the area of prevention—is absolutely necessary to be addressed and to be addressed with vigor.

Now we believe that the collaborative volunteer private sector multigovernment efforts based on that brotherhood that exists between the peoples of the Pacific and people of Hawaii represents a model, can address this issue. And, in fact, those of us on this panel believe that model may well be applicable to other parts of the country. Governor Waihee and Dr. Lewen, the director of health of the State of Hawaii, believe that there are many things that we learn as we serve in the Pacific that are applicable to Hawaii or applicable to core cities in the 48 States—the mainland—in Alaska.

And so it is not only the matter of providing services where necessary, but learning a great deal that we think can be applicable and importantly applicable. We believe, as my colleague dean has indicated—colleague deans—that the new Federal legislation, the Disadvantaged Minority Health Improvement Act which has passed the Senate—will assist us in addressing these kinds of issues. We hope that similar action in the House will make that act possible and, we will be able to proceed with vigor.

One final personal point I should like to comment on. It may be something you do not know, although you have known Mr. Trotter for some period of time. Before I met Fred Trotter almost 20 years ago, I had known of and had been a great respecter of his grandfather. I had not met with him, but his grandfather.

Also Frederick Trotter was one of the most outstanding Public Health Service officers in the commissioned officer corp of the Public Health Service and its 200-year history, a person who had made significant service in the control of smallpox, dengue, and plague throughout the globe, was assigned to Hawaii in the early 1900's to head the quarantine service and the Hansen's disease program, subsequently was seconded to become director of health.

He retired in Hawaii, continued as the director of health for Hawaii and continued an outstanding career. And as a fellow public health service officer, I knew of his career and wanted to mention for the record what a fine background your next speaker comes with.

PREPARED STATEMENT

Mr. Chairman, I would like to submit for the record the full text of my remarks plus the extended commentary on behalf of my 23 colleague deans of schools of public health of the United States and that will be the submission of their funding request for fiscal 1991 for public health programs under this committee's jurisdiction.

It is a pleasure to be here, Senator. I thank you very much.

Senator INOUYE. Without objection your full statement will be made a part of the record.

[The statement follows:]

STATEMENT OF DR. JERROLD M. MICHAEL

Mr. Chairman, I am Dr. Jerrold Michael, Professor of Public Health at the School of Public Health of the University of Hawaii, where I have served for 19 years, the past 18 as Dean of the School of Public Health. Prior to that I served for 20 years as a commissioned officer in the United States Public Health Service, retiring at the end of 1970 as Assistant Surgeon General.

It is my pleasure today to testify on one of the most unique and most rewarding collaborative activities that I have ever been involved in during my 40 years in the field of public health.

That unique opportunity is the State of Hawaii GOVERNOR'S PACIFIC HEALTH PROMOTION AND DEVELOPMENT CENTER--a historic partnership of the governments of the Pacific nations with the government of the State of Hawaii, the federal government of the United States, the private sector of health and medicine in Hawaii and the Pacific Basin, and the University of Hawaii.

The earliest strategic action on this issue came out of a meeting on addressing the significant health problems of the Pacific called by Senator Inouye and attended by the Asst. Secretary for Health, the Surgeon General and several of his Assistants some seven years ago. What followed was the first survey of health services and conditions in the Pacific conducted by the University of Hawaii in 1984.

The concept of the Center was indeed the brainchild of Governor John D. Waihee; recommended as a Pacific partnership for health in the first month of his tenure of office a little over three years ago. The Center concept has become an operating entity which has coalesced the major health and health-related resources present in Hawaii and the Pacific in a wholesome effort to contribute to the improvement of health status of the Pacific Islands and simultaneously to assist Hawaii in its own health care development.

Inherent in the mission of this Center is the recognition and desire to enhance the self-determination of the Pacific Island nations in managing and sustaining their own health systems as they deem appropriate.

Linked closely with the PACIFIC ISLAND HEALTH OFFICERS ASSOCIATION and the REGION IX OFFICE OF THE UNITED STATES PUBLIC HEALTH SERVICE in San Francisco, the Center has been funded through the collaborative contributions of the federal government and the State of Hawaii, along with significant donations from the private sector. The program has been carried out by volunteers from Hawaii, funded only for their travel expenses.

They have been able to: carry out remarkably effective programs in the treatment of otitis media (inner ear infection) in children; develop training programs for the control of hypertension and diabetes; provide short-term technical training for Pacific health workers in laboratory technology, radiology and facilities maintenance; enhance nursing and physician skills through in-service training; develop Pacific Island health professionals' skills in rehabilitation assessment, acute rehabilitation and home care for the disabled; increase the medical manpower available in the Pacific through the University of Hawaii Medical School's medical officers training program in Pohnpei; improve health information systems; establish hepatitis immunization and control programs; develop community health centers; conduct a comprehensive study of mental health and substance abuse; and, as I shall describe in a momemnt, conduct a comprehensive reassessment of the Pacific health services and conditions in that area of the Pacific known as the U.S.-related Pacific nations.

Those several Pacific nations are organized into autonomous governments which differ in their political relationships with the United States. Three of the jurisdictions--American Samoa, Guam and the Commonwealth of the Northern Mariana Islands--are known as the flag territories--those that hold territorial status with the United States. The other three jurisdictions--the Federated States of Micronesia, the Republic of the Marshall Islands and the Republic of Palau--are referred to as the freely associated states inasmuch as they hold semi-independent/quasi-sovereign status with the United States.

During the first two years of operation of the Governor's Pacific Health Center, the secretariat for its management was jointly shared with the Hawaii State Health Department under the inspired leadership of Dr. John Lewin, its Health Director, and the University of Hawaii's School of Public Health. Recognizing a need to place the Center in the private sector, the Governor urged the Center leadership to establish a continuing locus for the Center in a community-sponsored institution. Because of its long-term role and commitment to the Pacific, the Rehabilitation Hospital of the Pacific was selected for that site and it has so served for the past year. The able Executive Director of that Center is Professor Claire Hughes of the School of Public Health and the State Department of Health.

It is not difficult to credit the people who are responsible for the vision and the continuing support that have made this truly remarkable collaborative program work. I've already mentioned the Governor's important role in this undertaking and it is worth mentioning that the spirit of collaboration which is present in all the deliberations of the Center can be traced to his own personal influence on the peoples of the Pacific. He, himself, a person of Pacific heritage--a Hawaiian--has maintained a close political and state-to-state links with the various nations of the Pacific--from which, incidentally, many of the people of Hawaii owe their heritage. The Governor has promoted through a Policy Group, the full participation of health professionals and elected officials from all of the jurisdictions including that of Hawaii.

Dr. S.T. Han, the WHO Regional Director for the Western Pacific, has been of particular assistance in formulating plans based on the overall strategy for health enhancement in the Pacific. Dr. Han has been a continuing guide and counselor for these activities and a most welcome colleague. His support and guidance is critical inasmuch as what is done in one area of the Pacific must be relevant and consistent with what is done in other areas. Dr. Han's leadership, therefore, is critical to the success of the efforts.

Dr. Sheridan Weinstein, Assistant Surgeon General, U.S. Public Health Service, and long-term Regional Health Director of the U.S. Public Health Service, has for decades provided support for the activities that have made this Pacific health collaboration so productive. His support and that of the senior Senator from the State of Hawaii, Daniel K. Inouye, made it possible for the University of Hawaii to carry out in 1984, a full assessment of the health services and conditions in the U.S.-related Pacific jurisdictions. That study identified the important differences and the availability and accessibility of health resources in the Pacific. They are the same individuals who have provided the opportunity last year for a reassessment to have been made by the University's School of Public Health. It is not my purpose at this sitting to detail those conditions, except to reinforce the fact that in many ways the health conditions found in these Pacific nations parallel those of developing nations in Asia.

The overall findings of the most recent 1989 study, developed primarily by two of my colleagues, Professors Jonathan Raymond and Roylinne Wada, show that while the U.S. Pacific health systems have made slight yet measurable progress in nearly all of the areas first surveyed in 1984, nevertheless the systems and services reflect a low level of adequacy with the flag territories doing better than the freely associated states. The slight imnprovements may be attributed to internal resourcefulness and in large part to the external support received from the U.S. federal government and at least in part from the Governor's Pacific Health Center. Five areas of findings suggest directions for the health efforts in the Pacific for the future:

- o LEADERSHIP. There is a health leadership crisis in the Pacific. Senior health leaders are retiring with few persons with expertise available to take their jobs.

- o MANPOWER DEVELOPMENT AND TRAINING. Major health manpower shortages exist in the Pacific, and there is a need to develop a consistent and supportive plan which will assist in providing indigenous health personnel to serve the needs of the area.

- HEALTH SYSTEMS PLANNING AND DEVELOPMENT. None of the jurisdictions are pursuing deliberate development of their health systems through the process of planning and that is an area where additional effort is needed.

- RAPID POPULATION GROWTH. The Pacific Island jurisdictions are continuing to experience rapid population growth. This rapidly changing demography in the face of diminishing resources will create problems of significant dimension for the future.

- PUBLIC HEALTH NEGLECT. Finally, the most critical area is that public health and prevention continues to be neglected because of the need to emphasize repair or clinical health services and tertiary care. Preventable problems continue to add to the increasing health problems and economic burdens of the Pacific Island jurisdictions.

These are areas that the Pacific Health Center will assist in addressing in the future.

The collaborative volunteer private sector-multigovernmental effort which is based in the brotherhood that exists between the peoples of the Pacific, presents a model that may well be applied in other parts of our country and in other parts of the global community. The future holds a potential for an enhanced health promotion effort in the Pacific which not only addresses current and tangible problems of people of that area, but with its focus on health promotion, I believe that it can serve to reduce an unnecessary future economic burden on the United States.

That future is potential through the federal legislation addressing Pacific Basin minorities contained in Senate Bill 1606, the Disadvantaged Minority Health Improvement Act of 1989. That Bill was introduced in the 101st Congress, passed the U.S. Senate Committee on Labor and Human Resources on November 1, 1989 and the full Senate on November 21, 1989. At the adjournment of the Congress on November 22, 1989, the companion House Bill was not enacted, but it is hoped that action during the current session will provide the companion bill that will allow the Act, and in particular Title III, to be initiated.

Title III establishes the Pacific Basin Health Services Council and provides funds for the continuation of a variety of programs now being funded separately, and through the Governor's Pacific Health Center. The Pacific Health Center serves as a nidal point for the formal establishment of the Council and for the continuation of this worthy collaborative health effort.

Mr. Chairman, the person who has served with the Governor's Center and has provided the executive leadership throughout its history is with me today and will be testifying in some greater detail on the upcoming phase of operation of the Governor's Pacific Health Promotion and Development Center. That person is Mr. Fred Trotter, trustee of the Campbell Estate and Chairman of the Executive Committee of the Governor's Pacific Health Promotion and Development Center.

I would like to take the privilege of adding one footnote to what you may already know about Mr. Trotter. Mr. Trotter's grandfather, like myself, was a member of the Commissioned Corps of the U.S. Public Health Service. One of the most distinguished officers in the one hundred years of that Corps, he contributed significantly to the control of contagious diseases in the United States and in a number of its territories; and in the early part of this century, was assigned to work on quarantine operations in the Territory of Hawaii. He subsequently was secunded by the U.S. Public Health Service to become the State Director of Health, a position which he held for a considerable period of time even after his retirement from the Public Health Service. His work is a model for all of us in the field.

Thank you, Mr. Chairman.

ASPH REQUESTS $20.3 MILLION FOR THE U.S. SCHOOLS OF PUBLIC HEALTH IN FISCAL YEAR 1991

All of the academic public health programs listed here are authorized under Title III and VI of the Public Health Service Act (P.L. 100-607).

The supply and demand of public health professionals cannot be determined as precisely as those for physicians and nurses. Yet, in the last three reports to Congress on the status of health personnel in the U.S., DHHS concluded that shortages of personnel were likely in several public health specialists trained in schools of public health: epidemiologists, environmental health professionals including toxicologists and hazardous waste managers, biostatisticians, nutritionists, public health nurses and physicians trained in public health and preventive medicine.[1]

The following programs attempt to address the shortages of trained public health professionals in the U.S.

I. Student Support (Traineeships)

ASPH requests $4.3 million in FY91 funds for traineeships to students in Schools of Public Health.

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[1] See the DHHS "Sixth Report to the President and Congress on the Status of Health Personnel in the U.S." (June, 1988)

The program is intended to attract high caliber students and to offer the economically disadvantaged, especially minorities, an entry point into the system. The rising cost of tuition and other expenses will make it even more difficult for low-income students, particularly minorities, to afford graduate education in public health schools.

Furthermore, traineeships are important because many students undertake graduate study in public health at mid-career and have family obligations. Others have already accrued heavy debts from their previous education. The graduates, unlike many of the other health professions, do not enjoy lucrative incomes. Nearly 80 percent of the graduates are employed by governmental agencies, non profit organizations and universities. Their modest salary levels are reflected in a recent survey which showed the mean income for all 1986 graduates at $31,524 with half of the graduates making less than $28,000 (this figure includes physicians and dentists working in public health).

II. Special Projects

ASPH requests $5.0 million in FY91 funds to support the development of training opportunities in public health to meet emerging national priorities as outlined by DHHS in the Year 2000 health objectives for the nation. This program emphasizes projects in preventive medicine, to increase the numbers of students from disadvantaged backgrounds, and to improve access and quality of care, among others.

The recently released IOM report entitled "The Future of Public Health" said that the schools of public health should enter into collaborative ventures with public health agencies. Special projects will allow the establishments of links between the academic and public health practice fields.

III. Prevention Centers

ASPH requests $8.0 million in FY91 funds to support an emerging national network of prevention centers.

Initiated in 1986, five centers are currently funded by CDC. They are conducting research that focuses on ways to promote good health and prevent disease. Each center works closely with local health agencies as well as with providers of health services to develop new ways of promoting health and on improved methods of appraising health hazards and risk factors. In short, they are developing state-of-the-art prevention techniques. Located in the multi-disciplinary Schools of Public Health, the centers serve as demonstration sites for translating new knowledge into practice.

There is a need for additional centers. There are currently 12 approved yet unfunded centers that met the strict criteria of peer review. Needed is $8.0 million to start-up five to eight more prevention centers in FY91.

II. Preventive Medicine and Public Health Residencies

ASPH requests $3.0 million in FY91 funds to support residency training for physicians in preventive medicine in schools of public health and medical schools.

Healthy People underlined the need to increase the supply of professionals in this special practice area. Also an Institute of Medicine report, "A Manpower Policy for Primary Health Care," made several recommendations including one to increase the number of residency positions in preventive medicine. The GMENAC and COGME reports also urged support for preventive medicine training saying it was definitely a shortage area in medicine.

The chart on the following page outlines ASPH requests for FY91 and budget history of programs of primary concern to Schools of Public Health.

APPROPRIATIONS HISTORY (Millions)

	Final FY 1987	Final FY 1988	Final FY 1989	Final FY 1990	ASPH Requests FY 1991[1]
Institutional Support (Capitation[1])	$5.0	$4.7	$5.0	$3.0	--
Traineeships[2]	$3.0	$2.8	$3.0	$3.0	$4.3
Special Projects[2]	--	--	--	$1.0	$5.0
Preventive Medicine Residencies[2]	$1.6	$1.5	$1.5	$1.7	$3.0
Centers for Health Promotion and Disease Prevention[3]	$1.5	$1.5	$2.0	$4.0	$8.0

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[1] ASPH is requesting full authorization amounts; capitation is no longer authorized; special projects were enacted as a replacement.

[2] Traineeships are authorized by Sec. 621 of P.L. 100-607; special projects by Sec. 790 A; preventive medicine residencies by Sec. 788 (c). These programs are administered by HRSA.

[3] Prevention centers are authorized by Sec. 312 of Title III, P.L. 100-607. This program is administered by CDC.

STATEMENT OF FREDERICK TROTTER, CHAIRMAN, GOVERNMENTAL PACIFIC HEALTH, PROMOTION AND DEVELOPMENT CENTER, TRUSTEE, ESTATE OF JAMES CAMPBELL

Senator INOUYE. Now may I call upon a very dear friend, Mr. Fred Trotter.

Mr. TROTTER. Thank you, Mr. Chairman.

The comments by Dean Michaels are much appreciated. I am here this morning because my grandfather, Dr. Freddy Trotter's son had the wisdom to marry my mother and, I am also Freddy Trotter. So oftentimes I am thought of as being my grandfather's son. But I am not. I am his grandson.

Mr. Chairman, thank you very much for the opportunity to testify in front of you this morning. My name is Fred Trotter. I am a trustee of the Campbell estate and a Honolulu businessman.

I served as president of the original blue ribbon committee for the Governor's Pacific Health Promotion and Development Center and currently chair the center's executive committee. I have submitted the center's recent executive summary for your inspection.

Mr. Chairman, if you will allow me a minute. Opportunity does not always present itself to comment on things. Here some 5,000 miles away from my home, I would like to pay tribute to a woman who in my estimation made the most magnificent gift that has ever been made in, I think, in Hawaiian history. And that woman is Bernice Pauahi Bishop who gave everything she owned to create the estate now called Bishop estate and also to endow the Kamehameha Schools for the benefit of helping the Hawaiian people; 100 years later it is often in Hawaii that the Bishop estate does not get credit for what it has been able to produce.

And I would like to pay tribute to trustee Thompson and his colleagues for carrying on Bernice Pauahi's wishes 100 years later. In my estimation probably the most magnificent organization that will exist in Hawaii because it will exist in perpetuity.

I am here today, however, to make comment on health in the Pacific and to address many of the health issues that directly affect the families and health delivery systems in the United States, associated Pacific which include American Samoa, Guam, Commonwealth of the Northern Marianas, Republic of the Marshall Islands, Federated States of Micronesia, and the Republic of Palau.

The mission of the Governor's Pacific Health Center is: to improve the health status and quality of life for all peoples of the Pacific by enhancing the self-determination of Pacific Island nations in development and management of their own desired health systems. In my recent trip to that area, I learned that about 50 percent of the population of the Pacific Islands is under 15 years of age; 20 percent of children 6 years of age and under suffer from gross evidence of malnutrition induced by diet change.

That up to 25 percent of the population over 15 years of age display evidence of diabetes, again, due to dietary changes. And that the rapid population growth coupled with newly emerging health threats outpace most Pacific nations capacity to manage.

These statistics do not begin to represent the myriad of health problems plaguing Micronesia. I would like to focus my testimony, however, today on the transitional activities which mark the progress made in establishing the Governor's Pacific Health

Center. It has been commented on that the health center had its beginning at the University of Hawaii and the Department of Health.

However, recently the center has been moved to the rehabilitation hospital of the Pacific. It is now formally operating there. The center is located in close proximity to the largest medical complexes in Honolulu and staffed by a strong and capable team.

We have a half-time executive director, Claire Hughes, who also serves as a faculty member for the University School of Public Health and a full-time administrative assistant, Jo Ann Tsark. Both are native Hawaiians and experienced public health professionals.

The center's relationship with the rehabilitation hospital is an important one. The rehabilitation hospital serves as a resource and treatment center for the Pacific Basin and provides the center with full fiscal support.

I have been fortunate to have been a director of this hospital for over 10 years. The hospital owes its humble beginnings to you, Senator, and to this Congress. The center's funding record is a clear example of the commitment of Hawaii's public and private sector in making this specific partnership succeed.

For this fiscal year alone the executive committee has ranged approximately $268,000 in cash and in kind services. One-third from public State funds and two-thirds from the private sector. These moneys support the center's small staff and grants for Pacific health projects. In kind contributions run the gait from equipment to staffing, consultation, transportation, and the actual hands-on treatment of patients. The kind of collaboration is precisely what the Governor envisioned when he asked the public and private sector health community to work together for Pacific health.

Since its inception, well over $1 million of State and private funds have been expended. To illustrate how this partnership works, let me take you through just one of the programs funded for the last 2 years.

In 1987 the Pacific Island Health Officers Association comprised of the leading health official from each jurisdiction prioritized the problems identified in the 1984 health assessment alluded to by Dean Michaels. The priority list has served as the guiding document for the center.

Manpower development was identified as a top priority issue and last year the center awarded a grant to Dr. Paul Rudoy a pediatrician who was born in Argentina, which enabled him to take a team of health professionals to the Republic of Palau to work with the Pacific health workers in the management of otitis media, which is inner ear disease.

Inherent in this project was the use of indigenous students from the medical officer school in Pohnpei. To treat and to train health professionals and pair professionals in Palau to continue the work. All physician time in this project was donated by the Kapiolani Medical Center in Hawaii and the University of Hawaii School of Medicine. Grant money supported travel per diem and equipment cost.

Dr. Rudoy and his staff treated 250 children and adults in seven villages. Many times they had to walk many miles to get to these places. What is more important to medical students trained seven health assistants, one from each village, so they would be there to identify and treat future problems.

The center's activities and growing role in Pacific health is rapidly occurring on a statewide level. Hawaii is assuming a pivotal role in Pacific Basin health and is ready to serve as a resource and link to our Pacific neighbors and friends.

I might comment also, Mr. Chairman, that in my humble opinion, that the State of Hawaii offers the greatest opportunity for research, education, and training in health of any State that I know of in the sense that we have the kinds of tools and equipment. We have the people who can deliver the system, and we have a health industry that presently rates number three in total economic development in Hawaii.

As we prepare for possible funding from Senate bill 1606 and others the center, I think, has demonstrated its ability to pull together the different health community components by developing and coordinating resources and mechanisms, as well as administrative and fiscal strengths.

There are many needs in the areas we are discussing. One of the major hurdles is communications. Although telephone and fax machines provide fast and direct ties, building interpersonal trust relationships are a cultural necessity to maximize the value of these means of communication.

The center staff was recently invited to a meeting of the Pacific Island Health Officers Association in Pohnpei to talk about the center, to discuss possible funding sources from Congress, and the relationship of PIHOA to the health community in the Pacific. My staff and I met with the health officers in an informal meeting, which provided an opportunity to explore their concerns—and there were many. Discussions were extremely candid, and I am confident that this partnership will continue to work well together.

The important finding from that meeting was that periodic face-to-face meetings with PIHOA and their administrative staffs, though costly, will be key in maintaining this partnership.

I want to commend Continental Airlines, Mr. Chairman, because they have for 3 years funded 45 half-year tickets to this part of the world that is a very expensive place to get to.

My staff and I want to continue to schedule additional sessions as we set the wheels in motion for a long-term relationship. I want to relate to you a personal observation while in Pohnpei.

It is quite apparent from my recent trip to Pohnpei that the Japanese Government has extreme interest in this part of the world. I am sure you are aware of that. Two examples of these are, they are funding at no charge to the Pohnpei Government a two-lane paved road completely around the island, complete with modern bridges, culverts crossings. It must be an incredible expense and possibly a good addition to the island.

In addition, while I was visiting the Pohnpei hospital to get a feel of some the problems and programs, I bumped into a team of 18 Japanese eye specialists who were conducting eye exams. I am told that these Japanese doctors arrived with everything and have conducted four different eye exam sessions consisting of 400 to 500 people at a time. And as I observed their equipment, it is the latest eye equipment available anywhere in the world.

They are extremely well received by the people in Pohnpei. They are carrying on a much needed program. They even were doing eye transplants in the hospital. And I guess it is my way of saying that certainly other governments are aware of the need in this area. As I understand from talking to some of the doctors, this total effort was funded by a Japanese private corporation with the full support of the Japanese Government. I use that as an example of the tremendous need and the fact that other people are also seeing that need.

PREPARED STATEMENT

Mr. Chairman, I want to thank you for the opportunity to speak today. I hope that I have conveyed the enthusiasm that Governor Waihee and all of the Hawaii entities which make up the center feel about this venture. We are fully conscious that one of the things that Hawaii and the Pacific have in common is a struggle of its indigenous peoples for health, self-sufficiency and self-determination.

We feel strongly that this bond of the native peoples will provide a solid foundation to bring about change in the health status of which I know you are personally concerned.

I thank you very much for this opportunity.

[The statement follows:]

STATEMENT OF FRED E. TROTTER

Thank you for the opportunity to present testimony today. I am Fred Trotter, Trustee for the Campbell Estate and a Honolulu businessman. I served as President of the original Blue Ribbon Committee for the Governor's Pacific Health Promotion and Development Center, and currently chair the Center's Executive Committee.

Let me begin by saying that I view this legislation, S. 1606, the Disadvantaged Minority Health Improvement Act or 1989, as the means to address many of the health issues directly affecting the families and health delivery systems in the United States associated Pacific which includes: American Samoa, Guam, Commonwealth of the Northern Marianas, Republic of the Marshall Islands, Federated States of Micronesia and the Republic of Palau.

I learned recently that,

- about 50% of the population of the Pacific islands is under 15 years of age;
- that 20% of children 6 years of age and under suffer from gross evidence of malnutrition induced by diet changes;
- that up to 25% of the population over 15 years of age display evidence of diabetes again due to dietary changes; and
- that the rapid population growth coupled with newly emerging health threats outpace most Pacific nation's capacity to manage.

These statistics do not begin to represent the myriad of health problems plaguing Micronesia.

Gentleman, I would like the focus of my testimony today to be the transitional activities which mark the progress made in establishing the Governor's Pacific Health Center. The Center was moved to the Rehabilitation Hospital of the Pacific in July of 1989 and the office was formally blessed in November after staffing was complete. The Center is now located in close proximity to the largest medical complexes in Honolulu and staffed by a strong and capable team. We have a half-time Executive Director, Claire Hughes, who also serves as a faculty member at the University's School of Public Health, and a full-time

Administrative Assistant, Jo Ann Tsark. Both are Native Hawaiians and experienced Public Health professionals. The Center's relationship with the Rehabilitation Hospital is an important one. The Rehabilitation Hospital serves as a resource and treatment center for the Pacific Basin and provides the center with full fiscal support.

The Center's funding record is a clear example of the commitment of Hawai'is public and private sector to making this Pacific partnership succeed. For this fiscal year alone, the Executive Committee has raised approximately $268,000 in cash and inkind services. Approximately one-third comes from public state funds and two-thirds from the private sector. There monies support the Center's small staff and grants for Pacific health projects. In-kind contributions run the gamut from equipment to professional staffing, consultation and the actual hands-on treatment of patients. This kind of collaboration is precisely what Governor Waihee envisioned when he asked the public and private sector health community to work together for Pacific health.

To illustrate how this Pacific partnership works, let me walk through one of the programs funded by the center for the past two years. In 1987, the Pacific Island Health Officers Association, comprised of the leading health official from each jurisdiction, prioritized the problems identified in the 1984 Health Assessment conducted by the University of Hawai'i. That priority list has served as the guiding document for the Center. Manpower development was identified as a top priority issue and last year, the Center awarded a grant to Dr. Rudoy, a pediatrician, which enabled him to take a team of health professionals to the Republic of Palau to work with Pacific health workers in the management of otitis media (ear disease). Inherent in his project was the use of indigenous students from the Medical Officers School in Pohnpei to treat and to train health professionals and paraprofessionals in Palau to continue the work. All physician staff time in this project was donated by the Kapiolani Medical Center in Hawaii and the University of Hawai'i School of Medicine. Grant monies supported travel, perdiem and equipment costs only. Dr. Rudoy and his staff treated 250 children and adults in seven villages in Palau. However, what is more important, the medical students trained 7 health assistants, one from each village on how to identify and treat otitis media.

This is only one example, yet indicative of the nature of the projects that the Center funds and supports. Facilitating self-sufficiency is a role the Center takes very seriously.

The Center's activities and growing role in Pacific health reflect what is rapidly occuring on a statewide level. Hawai'i is assuming a pivotal role in Pacific Basin health and is ready to serve as a resource and link to our Pacific neighbors and friends. As we prepare for Senate Bill 1606, the Center has demonstrated its ability to pull together the health community by developing and coordinating resources and mechanisms, as well as, administrative and fiscal strengths which will lead to sound health projects.

There are areas that need immediate attention in order to strengthen our alliances and networks in the Pacific. A major hurdle will be the communications linkage. Although telephone and FAX machines provide fast and direct ties, building interpersonal trust relationships are a cultural necessity to maximize the value of these means of communication. The Center's staff was invited to a meeting of the Pacific Island Health Officers Association earlier this month in Pohnpei to talk about 1) the Center, 2) the potential funding from S. 1606, and 3) the relationship to PIHOA and the health community in the Pacific. My staff and I met with the health officers in an informal meeting which provided an opportunity to explore their concerns. Discussions were candid and I am confident that this partnership will continue to work ~~well together. The important finding~~ from that meeting was that periodic face-to-face meetings with PIHOA and their administrative staffs, though costly will be key in maintaining this partnership. My staff and I want to schedule additional sessions, as we set the wheels in motion for a long-term relationship.

Gentlemen, I thank you for this opportunity to speak today. I hope that I have conveyed the enthusiasm that Governor Waihee and all the Hawai'i entities which make up the center feel about this venture. We are fully conscious that one of the things that Hawai'i and the Pacific have in common is the struggle of its indigenous peoples for health, self-sufficiency and self determination. We feel strongly that this bond of the native peoples will provide a solid foundation to bring about change in the health status of which you can be proud.

I will be happy to answer any questions that you may have relating to my testimony.

Senator **Inouye**. Thank you very much, Mr. Trotter.

I would like to add a footnote to your opening remarks on Bernice Pauahi. I know that there are several here who have never heard of Bernice Pauahi. She was a princess, a direct descendant of Kamehameha the Great, the great-granddaughter of our first king.

And she as the direct descendant inherited the royal lands, and she bequeathed all of her property and all of her treasures to establish Kamehameha Schools.

At this moment, I would like to put on my other cap—chairman of the Defense Appropriations Committee. The panel here has spent much time discussing the plight and the problems and concerns of peoples in the Pacific. These are not citizens of Hawaii. These are not natives of Hawaii. These are not my constituents.

These are men and women who come from Guam, Samoa, the Northern Marianas, Marshall Islands, Micronesia, Palau. These are islands that were once called the trust territory of the Pacific. At the end of World War II, the United Nations selected the United States to serve as trustee of these islands. We requested that responsibility because of the strategically important location of these islands.

As some of you are aware some of the hydrogen bomb testings were done in these islands. Some of our important military facilities are presently located there.

At this moment dramatic change is occurring throughout this globe, not just in the European Continent, but also in the Pacific. Our negotiators are involved in a very important discussion with Filipino negotiators as to the future use of important bases there, a base at Subic Bay and Clark Air Force Base.

The Secretary of Defense recently visited the Philippines and he acknowledged the possibility that these negotiations may not succeed. And if that results, we may have to move. There are not too many places where we can move. We are no longer in the Southeast Asian Peninsula. We are no longer in Vietnam. Therefore, we have to look in the Pacific, and these are the islands that present possibilities.

And yet, the Government of the United States for some strange reason has ignored the importance of these islands. In fact, in the submission of the budget, there is no funding for the Pacific Basin. Now, if we are going to establish important bases in these islands, we better make certain that the natives there are friendly to our cause. We seem to go out of our way to ignore them.

And the role that Hawaii is playing by establishing such a center as the Pacific Health Promotion and Development Center should be done by the Federal Government, and we are the ones providing the moneys. Not a single dime from the Federal Government has gone into the endeavor so far. And we have been coordinating health programs in these islands. And this is not a State responsibility. But yet we in Hawaii realize that it is important to our Nation.

And so I hope that the Government of the United States takes note of this. For many, many years we have been carrying on this role. It is about time the Federal Government realizes its responsibility.

We participated in the establishment of the educational system in these islands. We participated in the establishment of their governments. We should keep in mind that these people are sovereign people. They could very easily refuse to provide space. And they can very easily throw us out.

And so I commend the State of Hawaii for the initiative it has taken and the many sacrifices it made. I requested these witnesses to travel long distances, so the record will show that unlike other States, we are not always asking. We are giving.

I wish to thank all of the Hawaii witnesses for traveling long distances to be with this committee this morning. I can assure one and all that their words will be taken very seriously. And when time comes for marking up the bill, I am certain my colleagues will look upon the request made with great favor.

Thank you all very much.

And now I am pleased to welcome special witnesses: Mr. John Taylor, Ms. Shawn Goldberg together with Ms. Donna Rosenthal, the executive director of the National Down Syndrome Society.

We thank the witnesses for waiting this long. You have been very patient. You have been with us since 9 o'clock this morning. But your words are very important to us. Every single word will be recorded. And I will make certain that my colleagues read every word of them.

STATEMENT OF DONNA M. ROSENTHAL, EXECUTIVE DIRECTOR, NATIONAL DOWN SYNDROME SOCIETY

ACCOMPANIED BY:

JOHN TAYLOR, VICTIM OF DOWN SYNDROME

SHAWN GOLDBERG, VICTIM OF DOWN SYNDROME

Senator **Inouye**. So may I first call on Mr. Taylor.

Mr. **Taylor**. Good morning.

My name is John Taylor. I have Down syndrome, which means, I have an extra 21st chromosome. On that 21st chromosome are the genes that cause Alzheimer's disease, leukemia, mental retardation, and even the shape of my eyes.

Studies using research dollars are finding these important genes. Research about chromosome 21 and the genes is the new way for research. About every other chromosome—we need research money, so that we can understand what these genes do. Then we will be able to work with them to find the cause and cure for mental retardation, Alzheimer's disease, leukemia, and Down syndrome.

Please make sure that NIH gets enough research money for Down syndrome. Thank you.

Senator **Inouye**. I thank you very much, Mr. Taylor. I apologize for the absence of my colleagues on this committee. But at this time there are 18 other committee meetings going on, so I am handling one. And they are scattered all over the Hill. But as I said, I can assure you that your words will be personally conveyed to all of them. You are a powerful witness.

And now may I call on Ms. Goldberg. Shawn?

STATEMENT OF SHAWN GOLDBERG

Ms. **Goldberg**. Hi, my name is Shawn Goldberg.

I am 12 years old. I have Down syndrome. I want to grow up like everybody else. I want to work as a hairdresser and work on people's hair. I want to learn how to drive, and I want to learn how to cook without my family.

We need research dollars to find a cure for Down syndrome. Please help us. Thank you.

Senator **Inouye**. Both of you have demonstrated that research moneys are not only justified but it is in our best interest. You have demonstrated to us that you are and you are capable of being contributing citizens of the United States, and we are very pleased to have you with us.

I can assure you that my colleagues will read your words. And I can promise you that there is a yes to all the requests you have made. That is my promise to you.

Thank you, Mr. Taylor, and thank you Ms. Shawn Goldberg.

And does the executive director wish to say a few words?

STATEMENT OF DONNA M. ROSENTHAL

Ms. **Rosenthal**. Just a few words please, Mr. Chairman.

There are 250,000 people in the United States today with Down syndrome. This genetic disorder occurs in 1 in every 800 births. We urge the subcommittee to commit the resources necessary to continue the work on Down syndrome and mental retardation by allocating research funds to the National Institute on Child Health and Human Development for the next step in basic research on chromosome 21.

As John has said, this research impacts not only on Down syndrome, but also Alzheimer's disease, leukemia, and mental retardation. If the subcommittee restores the budget reductions currently proposed and increased funding, our hopes for progress in unlocking the genetic secrets that affect the lives of so many children and adults will be closer to reality.

PREPARED STATEMENT

And I really want to thank you very much, Mr. Chairman, for allowing, to testify today. We are very proud to be here. And I hope that John and Shawn can come up and personally meet you at this moment. And thank you for your support.

[The statement follows:]

Statement of Donna M. Rosenthal

On behalf of the National Down Syndrome Society, I would like to thank the subcommittee for this opportunity to present testimony. The National Down Syndrome Society is a not-for-profit organization dedicated to discovering the causes and treatment of Down syndrome and its related illnesses of Alzheimer's disease and childhood leukemia. This genetic disorder, which causes mental retardation, occurs in one out of every 800 births, and affects more than 250,000 people nationwide.

In the past 10 years, the National Down Syndrome Society, with the guidance of a prestigious science advisory board chaired by Dr. Charles Epstein of the University of California at San Francisco, has sponsored science symposia to bring together internationally recognized scholars and scientists to thrust the research forward in the areas of molecular genetics, oncology, immunology and the psychology of Down syndrome. The society has also established a science scholar award program to support outstanding young scientists and to encourage them to make Down syndrome research their life's work.

Down syndrome is present when chromosome 21 occurs in triplicate form. Moreover, the genes on the 21st chromosome cause many well known illnesses.

If we can discover and treat the causes of Down syndrome, not only will this have an effect on the one in every 800 births which is a child with Down syndrome, but it will also prevent the large number of miscarriages experienced by women of all ages that result from chromosomal disorders.

If we can discover and treat the causes of Alzheimer's disease which pathologically affects every person over age 35 with Down syndrome, we will hopefully have the answers to the debilitating disease which also affects older adults in the general population.

If we can discover and treat the causes of childhood leukemia, it will affect both children with Down syndrome who suffer at a rate four times the norm from this illness, and children in the population at large who are affected by this lethal cancer.

If we can discover and treat the causes of mental retardation, the impact will be felt not only on children with Down syndrome, but on many other children born with related problems.

Chromosome 21 is the first chromosome to be mapped and is a prototype for the federally funded Human Genome Project. Moving gene by gene, researchers are unraveling the blueprint of chromosome 21 which contains genetic information that will unlock the answers to Alzheimer's disease, childhood leukemia, and mental retardation. At the same time researchers are searching for the basic answer to nondisjunction, or why there is an extra 21st chromosome which results in Down syndrome.

The next phase will focus on the actual identification of each gene and its impact on these illnesses. The final phase will be the study of how to manipulate these genes so that the illnesses can be prevented or cured; and of course, how to prevent the occurrence of the extra chromosome. Once again, chromosome 21 will be in the forefront and will be a prototype for research.

The subcommittee is well aware of the budget pressures on the research activities of the National Institutes of Health. Many biomedical research projects must be limited as a result of the available funding. Researchers who do receive funding are subject to downward negotiations and other limitations that squeeze the research projects to their bare bones.

Our triumphs continue in spite of these limitations. However, it would be a travesty for all of that pioneering work to be slowed now, when progress on chromosome 21 is leading the way for researchers in other areas.

The National Down Syndrome Society urges the subcommittee to commit the resources necessary to continue the work on Down syndrome and mental retardation by allocating research funds to the National Institute on Child Health and Human Development for next-step basic research on chromosome 21. If the subcommittee restores the budget reductions currently proposed, our hopes for progress in unlocking the genetic secrets that affect the lives of so many children will be closer to reality.

Senator **INOUYE**. Oh, I would love to do that. I want to thank John, because I was just telling the staff assistant here, I was not aware that the 21st chromosome had an effect on Alzheimer's and leukemia. We are always learning something. And thanks to you this committee will have something else to work on. I did not realize that the 21st chromosome affected more than Down syndrome. I thank you very much for that information.

Mr. **TAYLOR**. Thank you.

Senator **INOUYE**. Thank you, John, and thank you, Shawn.

STATEMENT OF KENT KOTH, CAMPUS COMPACT, GRINNELL COLLEGE, GRINNELL, IA

Senator **INOUYE**. Now, it pleases me to call upon Mr. Kent Koth of Grinnell College of Grinnell, IA.

Mr. Koth, welcome, sir.

Mr. **KOTH**. I am glad to be here.

Mr. Inouye, and members of the committee, I am Kent Koth a senior at Grinnell College in Grinnell, IA. I am here to talk about the ACTION student community service grant.

Over 1 year a ago several friends and I created the alternative happy hour program which links Grinnell students with children from the inner city of Des Moines. The program has enabled me to become friends with children like Twanna Harris, a happy and loving 8-year-old girl.

Through my friendships with these children, I have learned about their experience of growing up in an impoverished drug-ridden environment. Perhaps more importantly, I have experienced the joy of helping empower other human beings.

This past winter I organized an alternative winter break in Des Moines for 30 Grinnell students. The week provided the group with further insight into inner-city issues. In addition our activities during the week provided valuable assistance to 10 social service agencies in Des Moines.

Over the spring break there are three more Grinnell alternative breaks: One in Portland, OR, focusing on homeless issues; another in Des Moines working with children, and a third in South Carolina at a habitat for humanity work camp, where I will be returning to this evening.

These programs would not have been as successful without the assistance of the Grinnell College Community Service Center. The community service center aided in publicity, transportation, and coordination of all these programs. In addition, the community service center has been instrumental in developing over 26 new service opportunities since its creation 2 years ago.

In 1988, Grinnell College received an ACTION student community service grant, which has allowed the community service center to achieve the success it has today. The center has provided a vital link between students and the community. With the ACTION student community service grant Grinnell students would not have experienced the fulfillment of empowering others, and community social service organizations would not have had the volunteers which they have needed.

The success of the ACTION student community service grant at Grinnell is not unique. A total of 21 programs in 43 States are currently funded through the ACTION grant. ACTION student community service grants have been successful nationwide.

There is some confusion that ACTION student community service grants and FIPSE innovative projects for community service are duplicative projects. These grants are not identical. In my written testimony I detail the differences between these programs.

Today either members of the Labor, Health and Human Service, and Education, Appropriations Subcommittee are considering the funding of this ACTION agency program. I urge you to restore and expand the funding for the ACTION student community service grants. This modest investment of Federal funds in this program has assisted thousands of college students to become active in their communities.

PREPARED STATEMENT

Hundreds of college students whose schools have ACTION student community service grants could be here today telling their stories. If funding for the grant is not cut, students will continue to experience the fulfillment through service which I have spoken of today. ACTION student community service grants are an investment in America's students and the communities in which they live.

[The statement follows:]

STATEMENT OF KENT KOTH

Mr. Chairman and Members of the Committee:

I am Kent Koth, a junior at Grinnell College in Grinnell, Iowa and I am here to talk about ACTION's Student Community Service grants. I became friends with Twanna Harris, an enthusiastic eight year old, over a year ago. Twanna's family lives below the poverty level and resides in an area of Des Moines, Iowa, where gangs, drugs and teenage pregnancy are a way of life. I met Twanna through a volunteer project which I created with several peers and the help of the Grinnell College Community Service Center. The project, dubbed the "Alternative Happy Hour Program", links Grinnell students with children like Twanna. From my interaction with her and the other children in the neighborhood, I have developed a much greater understanding of the crisis in the inner city. My relationship with Twanna and my time in Des Moines has changed my life. I plan to dedicate my future energies to help empower disadvantaged young people from impoverished areas like Twanna's neighborhood.

This past January thirty peers and I spent a week of our winter break living and volunteering in the inner city of Des Moines. We slept on the floor of Trinity United Methodist Church and woke to the exuberant voices of one hundred neighborhood children (Twanna was one of these children) who live on or near the poverty level and come to the church for a free breakfast. Each day we helped serve breakfast to the children and provided assistance with Trinity's tutoring project. During the day we volunteered at Habitat for Humanity, the Catholic Worker House, the Des Moines Coalition for the Homeless, the Model Cities pre-school, and several other social service organizations. Each evening a representative from one of these organizations gave a presentation to our group on a specific poverty related issue. Through this "Alternative Winter Break", I added to my previous knowledge of urban poverty, helped others in need, and made friendships through service. From this experience I felt compelled to continue to volunteer to work for social justice.

The "Alternative Winter Break" and the "Alternative Happy Hour" would not have succeeded without the assistance of the Grinnell College Community Service Center. The center provided assistance in publicizing the programs to the campus, helped with transportation needs, and gave us an initial base from which to begin to organize both programs. The Community Service Center's support of the Des Moines programs is just one example of the significant impact that it has had upon the Grinnell community.

In 1988, Grinnell College received an ACTION Student Community Service (SCS) grant to establish the community service center. The Student Community Service program is nationwide and aims to enhance students' learning by enabling them to serve as community volunteers. By participating in projects that help eliminate poverty and poverty-related problems, volunteers gain the wide-ranging educational benefits of responsible community service. Local SCS projects are sponsored by school and community-based non-profit organizations, both public and private. SCS volunteers serve on a part-time basis, without pay and in many cases earn academic credit for their participation. Community organizations work closely with SCS sponsoring institutions, who develop support for the program after the grant ends.

The SCS grant has had a significant impact on Grinnell. Since the community service center opened in 1988, it has provided a vital link between the students and the community. Volunteer opportunities for students have expanded from three to thirty programs which range from weekly student visits to an elderly care facility, to a telephone hotline for victims of domestic violence, and of course, to our activities in Des Moines.

The Community Service Center not only enables students such as myself with a means to become active in the community, it also provides community organizations in need of volunteers with a college contact person and helps bridge the gap between the community and college students.

Grinnell College has benefited significantly from the ACTION Student Community

Service grant. Many students who were not previously involved in the community have now become active participants in service projects. The college administration has recognized the significant successes of the center and will support it once the government funding ceases. President Drake is a member of Campus Compact, a national group of 230 college and university presidents who are committed to supporting and enhancing collegiate community service activities. ACTION Student Community Service grants can help to spark institutionalization of other campus community service programs around the country.

A total of 121 programs in 43 states are currently funded through the Student Community Service grants. 62 are colleges and universities helping to provide an average of 9669 volunteer hours per project. Today, you, the members of the Labor, HHS, and Education Appropriations Subcommittee are considering the funding for this ACTION agency program. Support for Grinnell's Community Service Program, and the many other programs like Grinnell's, has changed many students' perspective of the world.

Many students have experienced the exhilaration of helping to empower others as a part of their education. This wouldn't have occurred to such a significant extent at Grinnell if it had not been for the ACTION grant. At a recent national conference for students involved in community service, many discussions centered around support for appropriate orientation and training for volunteers, and consistent outreach and cooperation with the community. Many students are struggling to develop programs without a specific administrative office or individual to provide support or assist them. Students have succeeded in their efforts, but there is tremendous student potential that needs to be tapped. ACTION Student Community Service grants can increase both the number and quality of programs at colleges and universities.

There were some questions by members of Congress about the differences in the ACTION Student Community Service grants and the FIPSE (Fund for the Improvement of Postsecondary Education) Innovative Projects for Community

Service. Both programs are important and complementary to the collegiate community service field. These two grant programs are not duplicative. They both support community service and have overlapping constituents, but the focus of each program is quite different and the recipients are not limited to higher education institutions.

Major differences in the programs are that the FIPSE grants encourage students to do community service in exchange for educational services or financial assistance. They are only available to students at postsecondary institutions and the awards do not require a local match. ACTION grants are open to a greater variety of students in secondary, vocational or postsecondary schools. A local match is required and the objective of the program is to encourage students to volunteer in service projects addressing poverty-related issues in their communities, in order to enhance their education.

Finally, as a college student of the 1980's, I feel frustrated about the perception that my generation is the "me generation". This accusation is simply not true. College students are not apathetic and self-serving as we are often accused. The major problem with my generation is that we have not been presented with the opportunity to demonstrate our potential. We have not realized that our time and energy can make a difference. With the help of ACTION grants and subsequent development of community service centers, college students will become empowered, active American citizens. ACTION grants are an investment in America's future and I urge you to support their continuance.

Senator INOUYE. I thank you very much, sir. And I want to commend you and your fellow classmates on your campus and those fellow students on other campuses for a job well done. And this is voluntarism in the best sense of the word. And apparently your work has been so good that the administration decided to double your appropriations request.

Mr. KOTH. And I hope that you go along with that.

Senator INOUYE. It is one of the few projects that have been not only supported by the administration but doubled. So you know you must have done well.

Mr. KOTH. Thank you.

Senator INOUYE. Congratulations.

STATEMENT OF JEAN McGUIRE, EXECUTIVE DIRECTOR, AIDS ACTION COUNCIL

ACCOMPANIED BY URVASHI VAID, EXECUTIVE DIRECTOR, NATIONAL GAY AND LESBIAN TASK FORCE

Senator INOUYE. Our next two witnesses represent the National Organizations responding to AIDS. First, may I call on Ms. Urvashi Vaid, the executive director of the National Gay and Lesbian Task Force; and Ms. Jean McGuire, executive director of the AIDS Action Council.

Ms. McGUIRE. If it is OK with you, Mr. Senator, I am Jean McGuire, I would like to go first and have Ms. Vaid follow me up if that is all right.

Senator INOUYE. Fine.

Ms. McGUIRE. I am Jean McGuire. I am the executive director of the AIDS Action Council. Our organization represents the interest of AIDS service organizations around the country including quite a few in the State of Hawaii. I am here today along with Urvashi in the role of cochairs of a coalition that has become very familiar here on the Hill called the National Organizations Responding to AIDS. It is over 150 national agencies that in some respect are responsible for meeting the challenges of the epidemic at local, State, and national levels in terms of providing care, prevention education, and research-related activities.

So we are here today to present something that has already been submitted for the record, our broad appropriations document. I am going to give an overview, and Urvashi is going to give a targeted analysis of some of the programs that we are recommending increases for.

I particularly appreciate the opportunity to be before you today. And I think what I would like to do, since my full statement has been submitted for the record, is outline why I think it is so very important that the committee duly consider a significant increase in terms of the AIDS budget this year. And I think that is because of the juncture that we will find ourselves at during this upcoming fiscal year, a juncture that is really quite significant in terms of being a historical benchmark.

First of all, during the fiscal year for which you will be allocating funds, we will see the doubling of the national AIDS caseload from what it was when we began this current fiscal year.

Senator INOUYE. May we have a short recess.

[A brief recess was taken.]

Senator INOUYE. We had a little crisis, please, proceed.

Ms. McGUIRE. That is quite all right. I am afraid we all have far too many of them. In fact, I am talking about one.

What I was indicating was that I think I am urging the committee—we are urging the committee—to be very thoughtful about some significant increases that I know run in the face of the budget constraints that you are facing this year. And we are doing that because we believe that the experience that is about to befall jurisdictions around the country—including in Hawaii—is going to be cataclysmic. You cannot double the caseload of an infectious disease like this that has the impact that it has had on hospital utilization, on primary health care utilization and all of the poverty health structures and not have to be responsive in some way, so that you do not diminish access to health care that people who are generally poor are also experiencing.

So during this fiscal year that is coming up, we will see that doubling of the caseload. And in addition, we are going to—and we will be beginning—a hallmark of sorts—the second decade of the epidemic, a time where we must be aggressive about the things we have yet to do anything about, which is essentially respond to the care agenda that is associated with this disease.

And I guess there is another thing that I think is going to be very significant about this fiscal year. And that is the fact that the largest increases in AIDS caseloads are going to be in nonmetropolitan areas and in areas like your State.

It is not going to be the significance of the increases in New York and San Francisco that we have seen over the previous 9 years. What we already know and what Senator Kennedy pointed out, when he introduced his major AIDS initiative 2 weeks ago, was that nonmetropolitan areas are seeing as much as 40-percent increases in their caseloads. And while their numbers are never going to be New York's and San Francisco's the impact is going to be relatively the same.

So we cannot afford to ignore the fact that there needs to be a national and a systemic response. The budget that we have proposed for you requests approximately $1.2 billion beyond the President's request.

And I would point out to you, though, when we use the President's request as a benchmark that it is also good to remember that last year for the fiscal year we are already in his own public health service requested $2 billion and got $1.5 billion. So our increase above the request does not begin to reflect the fact that the public health service knew that more money was needed already and did not get it.

In our document you will see that the greatest increases we have allocated in the arena of care. And they get differentiated along two lines: one is impact AID, which has been well-framed in the proposal that Senator Kennedy has put forward to the full Senate for consideration in terms of the emergency care AIDS resources act. And we believe that that bill does a combination of both well-recognizing the particular disasters that California and New York are experiencing, not unlike the disasters that we have responded to in terms of earthquakes and hurricanes and other such problems in the past.

But it also recognizes these needs of the nonmetropolitan areas, including jurisdictions within your State, that need to be able to prepare for the significant caseload increase that they are going to experience too, even though it is not going to be of the same size.

The other thing that we think is vitally important is that your committee has been particularly generous in allocating dollars to research, so that we now have information about how to prolong the lives of people who are affected by this disease. But that is relatively meaningless, if we cannot get them access to those early interventions. And so the other significant major infusion of funds that we are recommending is in terms of early intervention, so that the promise of a longer life will not just be a promise to those that are rich. That is not a demarkation that we can afford to sustain in the context of this disease.

Obviously, because of what we know that we have been able to gain in the arena of research, we know that we are not done. And that that continued support for NIH's good activities in that area has to be contained. And we also need to be looking at an arena that I think we are reminded of every time we think of both the tremendous care needs we face as well as the tremendous research promises that we have and yet not the full promise of saving a life.

And that is that we must reinvest in the prevention agenda. We must reassert and, in fact, claim some type of a national initiative to prevent the spread of this disease, particularly, as we are seeing it very unfortunately expand among the college age population that you were just recognizing for some of its very good work.

PREPARED STATEMENT

So I am going to stop at this point and ask Urvashi to particularly focus on the prevention agenda. Because I think when we talk about research and care, it is an agenda that can get lost very easily, very much because we have a tendency to ignore preventive health in this country anyway.

And I commend to your full review the full document that the national organizations have submitted.

[The statement follows:]

STATEMENT OF JEAN McGUIRE

The above signed members of the coalition National Organizations Responding to AIDS (NORA) join in urging $2,874,744,000 in spending for AIDS by the Public Health Service in fiscal year 1991. This request is about $1.2 billion above the President's request and $1.3 billion above current spending levels.

We support the largest growth in treatment and direct care programs because this has been the most neglected of the three areas of federal responsibility. As this nation faces the doubling of the AIDS caseload before the end of FY 1991, major new initiatives by the Federal government are required to provide care for those citizens and families affected by the epidemic. Assuring access to primary, acute, and long-term care services, as well as to life-prolonging drug treatments, remains the central priority in funding increases we propose in FY 1991. The major new increases proposed in this document are targeted to impact aid and early intervention initiatives necessary to provide disaster relief to the hardest hit jurisdictions and access to treatment.

The new fiscal year must also be the time when Federal programs reflect the expanded definition of AIDS prevention. Traditional education and behavior change programs must continue to grow to prevent further infection with HIV. But we must also understand that the research community has now given health care providers the tools to prevent or delay the onset of AIDS for those already infected with HIV, and Federal prevention and care programs must reflect this new reality.

The need for research does not stop with progress toward early interventions. We are far from a cure and a vaccine -- or a full understanding of HIV transmission. This work must continue and must receive increased resources. We remain convinced that AIDS research dollars should be earmarked within the NIH and ADAMHA budgets. Congress must give clear direction to the agencies regarding the priority of AIDS research. However, we remain concerned, as we have been since the beginning of the AIDS epidemic, that increases in AIDS funding not come at the expense of other important biomedical and behavioral research. We are disturbed by the inadequate levels of funding provided for non-AIDS in the FY 1991 administration request.

Not included in the PHS recommendations detailed in this document are expansions of Medicaid coverage for persons with AIDS and HIV infection. Critical to the long-term resolution of the health care access and delivery issues associated with AIDS are proposals pending before the Congress to expand Medicaid entitlements for persons with HIV infection who are not yet disabled and increased reimbursement rates for hospitals caring for persons with AIDS. Without these modifications in Medicaid, literally thousands of persons with HIV infection will face unnecessarily rapid progress to AIDS in the years ahead, and many hospitals around the country will be forced to make decisions regarding the rationing of care between indigent patients and persons with HIV disease as the AIDS burden overwhelms them.

NORA COALITION PROPOSED FUNDING LEVELS FOR AIDS IN FY 1991

PUBLIC HEALTH SERVICE
(In thousands of $)

Agency	FY1990	FY1991 (Pres.)	FY1991 (NORA)
AHCPR	8,474	10,505	10,505
ADAMHA	214,647	229,669	324,000
CDC	442,826	509,103	985,103
FDA	56,220	63,236	71,000
HRSA	112,503	72,679	524,600
NIH	743,532	800,146	950,000
OASH	7,676	8,523	8,523
IHS	------	1,013	1,013
TOTAL PHS	1,585,878	1,694,892	2,874,744

ALCOHOL, DRUG ABUSE AND MENTAL HEALTH ADMINISTRATION

1991 NORA Recommendation: $324,000,000
1991 President's Request: $229,669,000
1990 Appropriation: $214,647,000

The Alcohol, Drug Abuse and Mental Health Administration is the federal government's lead agency in developing new ways to prevent the spread of HIV, in dealing with the drug abuse aspects of the epidemic, and in addressing the psychosocial ramifications of the disease. ADAMHA also conducts biomedical research in conjunction with NIH, particularly relating to HIV infection and the brain.

The coalition believes prevention should remain the top priority of ADAMHA, particularly given the long road ahead for development of a vaccine. We are concerned that the President's budget once again gives a disproportionate share of limited resources to neuroscience activities. The expanding demographics of HIV infection also require renewed attention to this prevention: insufficient research has been conducted regarding successful HIV prevention strategies among ethnic-minority homosexual and bisexual men, sexual partners of drug users, and adolescents -- all of whom are becoming infected at increasing rates. Priority setting in this area should be dictated by demographic incidence. We are pleased to note that ADAMHA's FY 1991 request begins to move programs in that direction.

While not part of the AIDS budget, ADAMHA's role in preventing and treating drug and substance abuse is a central part of the fight against AIDS. We continue to be disappointed at the Administration's low level of commitment to prevention and treatment relative to the resources allocated to the war on drugs. We also believe that the ADM block grant should be administered in a manner reflecting the importance of AIDS among drug abusers.

The NORA Coalition supports the important research under way regarding neuroimmunology and psychoneuroimmunology that is not undertaken by other PHS agencies. Research into the interaction of drugs of abuse and HIV and drugs and the immune system are also important new areas directly relevant to the understanding and prevention of HIV. We believe, however, that it is important to assess what level of overlap exists between NIMH's work in this area and that of the NIH.

The NIMH's work on AIDS Dementia Complex is important. We are concerned, however, by the multiplicity of HIV-related natural history cohort studies undertaken by NIH, NIMH, and CDC. More coordination of research questions among the agencies might reduce the need for multiple cohorts, deriving valid data at a far lower cost.

Instability in funding for research and services continues to undermine the success of ADAMHA AIDS efforts. Funding fluctuations create a level of uncertainty for researchers and service providers alike, reducing potential interest competing for ADAMHA's HIV-related programs.

The NORA Coalition proposes that funds be provided beyond the President's request to support the following activities:

o $20 million beyond the President's request are needed to restore to the FY 1990 level of $33.6 million the drug abuse outreach demonstration programs. Early data from these projects suggests that it is possible to develop interventions that are highly successful in changing high-risk drug using behaviors, linking users with health care systems, and moving them off the streets and into treatment. Given that drug-related infection is the fastest growing segment of the epidemic, ADAMHA should not be phasing out these programs in FY 1991.

o $17 million should be added to maintain the number of new and competing prevention research grants at the FY 1990 level. Funding fluctuations create a chilling effect on researchers interested in studying HIV-related issues.

o $10 million are required to properly fund ADAMHA's randomized field trials of prevention interventions. ADAMHA is to be commended for initiating this long overdue program, but it can only generate the data needed if adequately funded. The $2 million in funding requested in the President's budget would not allow for creation and assessment of sound programs in multiple locations. Design of these trials should involve the CDC's prevention staff and the results of the trials should be incorporated into the CDC's prevention efforts.

o $12 million are required to fund the mental health services research demonstration program authorized by Congress in P.L. 100-607. Failure to include this in the President's request reflects ADAMHA's lack of commitment to service-based research.

Mental health services are becoming an increasingly important component of HIV-related care and prevention, particularly as diagnosis is made earlier in the disease progression and there is a significantly longer life expectancy. These services also are an important component in sustaining behavior changes. Only technical assistance for this program is included in the NIMH budget, assuming that this program will be implemented elsewhere. However, the President's budget request does not fund this program elsewhere in the PHS. We believe the entire program should be part of NIMH's mission and funded at the $12 million level.

o $20 million in grants should be provided to community based prevention and service organizations focusing on drug users. Such community based efforts have been extraordinarily successful in targeting gay community prevention efforts and should be replicated for drug users.

o $10 million should be provided for outreach training and support services for substance abuse and mental health AIDS service providers to focus on outreach workers and volunteer counselors.

o $5 million is needed for research-services collaborative efforts. With an increased understanding of HIV-related behavior change in the research community, efforts must be made to bring together AIDS service providers and social scientists, including the linkage of grants issued by ADAMHA, HRSA, and the CDC in this area.

CENTERS FOR DISEASE CONTROL

1991 NORA Recommendation:	*$985,103,000*
1991 President's Request:	*$509,103,000*
1990 Appropriation:	*$442,826,000*

The Centers for Disease Control is the lead agency for HIV-related prevention activities within the Public Health Service. In that role, the NORA Coalition believes that the CDC has a responsibility to prevent primary infection with HIV, which is the object of most of its activities, and to prevent or delay, to the degree medically possible, the development of AIDS among those who already have HIV infection. It is the latter role that is the focus of our recommendation for increases in the CDC budget beyond the President's request.

The Coalition supports the increases requested in the President's budget. We especially want to highlight several of the initiatives included in the Administration request.

Increased funding for street outreach, for prevention among women and infants, and for prevention among youth are particularly important. The demographics of HIV infection point to these populations as the most vulnerable, and the least likely to have been successfully reached with the HIV prevention message. In developing these programs, we hope the CDC will be particularly mindful of the needs of gay and bisexual youth and minorities and the need to target these populations within each program.

The evaluation of alternative counseling techniques is long overdue. The prevention effort has been hampered by our failure to systematically evaluate HIV education and prevention programs. This assessment of counseling is an important first step in the right direction, and should involve the expertise of ADAMHA in this area.

The sentinel seroprevalence studies, known as the family of surveys, have provided invaluable information regarding the extent and progress of HIV infection in a number of subpopulations. The Coalition strongly supports the continuation of these studies and continues to believe these are a preferred source of information regarding prevalence of HIV infection than the proposed national seroprevalence study. While no funds are requested in the FY 91 appropriation for this very costly project, we are concerned that the CDC will attempt to redirect some of its funds to implement the household study. We believe more research is needed before moving forward with this study.

The NORA Coalition proposes an increase of $376 million, for a total of $500 million, in funds available for HIV counseling, testing, prevention education, and early intervention. We believe such a dramatically expanded program should have two goals: (1) to counsel those at risk for HIV, whether positive or negative, regarding behavior changes that can prevent further exposure to or transmission of HIV, and (2) to provide for those already infected with HIV but not yet symptomatic the opportunity to consider treatments that have been shown to delay the onset of symptoms. We believe this fits well within the mission of the CDC since both objectives are designed to prevent the transmission or onset of disease.

The President's budget request assumes only a modest increase from $117 million to $124 million for counseling and testing services. We believe this is woefully inadequate at a time when the CDC is estimating that more than 500,000 people are in need of early intervention services. The CDC also estimates that most of these people do not know their HIV status. We believe that the CDC should be provided the funds necessary both to provide the testing and counseling opportunities and to make sure that those found positive have access to the early interventions.

We are also concerned that the increased demand for testing will further diminish the portion of counseling and testing resources devoted to counseling. It is already apparent that many counseling and testing sites devote insufficient time for effective counseling; without additional resources this could exacerbate the problem -- further weakening the value of testing.

The expanded counseling, testing and early intervention program should have four parts: (1) pre- and post-test counseling and prevention education about HIV, including a discussion of behavior changes and medical choices available for those who might test positive; (2) HIV testing services; (3) follow-up immune profiles for those who test positive to HIV to determine whether additional medical care is needed; (4) funds for early intervention drugs to be provided by either testing agencies or referral agencies for those without third party coverage. This program could in part be executed through expansion of existing arrangements with alternative HIV testing sites and the array of STD clinics, family planning clinics, TB clinics, outpatient hospital clinics, and community health centers already providing HIV-related testing, counseling and other services. We expect this program to be implemented cooperatively with HRSA.

The Coalition continues to support the CDC's funding of community based AIDS prevention and education programs among all groups associated with HIV to bring about fundamental changes in behavior and to reinforce those behavior changes that may be difficult to sustain over long periods of time. The CDC must broaden its outreach as new groups at risk are identified, without ignoring the continuing prevention needs among groups originally associated with HIV infection.

In recognition of the important basic prevention work that still needs to be implemented through the federal government's AIDS efforts, the NORA Coalition supports an additional $100 million in funding of community based prevention efforts. If these funds are channelled through the state health departments, a sound monitoring system must be established to assure that these funds actually reach community based organizations.

While we are pleased to see the evaluation component associated with counseling, we remain concerned at how little evaluation of other education and prevention programs has taken place. We are much too far along in our prevention efforts to have so little information about which approaches are successful and, therefore, ought to be replicated. To compensate for this, the Coalition proposes that Congress require a cross-program evaluation on the basis of information available from existing projects and data available from ADAMHA. Such evaluation can be one of the cornerstones of a national prevention strategy still lacking in the CDC's programming.

While not part of the AIDS budget, we support an increase to $173 million for STD prevention and control from the Administration's level funding of $81 million. The prevention and control of sexually transmitted diseases is directly related to the course of the AIDS epidemic. The behavior changes that can prevent the spread of STDs are the same that will prevention sexual transmission of HIV. This linkage is made more compelling by the role of STDs as cofactors in transmission of HIV. This substantial increase is necessary to address the alarming increase in formerly controlled STDs among heterosexuals, which could portend dramatic increases in HIV transmission as well.

HEALTH RESOURCES SERVICES ADMINISTRATION

1991 NORA Recommendation:	*$524,600,000*
1991 President's Request:	*$ 72,679,000*
1990 Appropriation:	*$112,503,000*

The Health Resources Services Administration is the lead federal agency in developing models of HIV social and health care delivery throughout the country. The Coalition is greatly disappointed that the Administration has recommended a 35 percent decrease in HRSA's funding for FY 1991. This is an unacceptable proposal for a year during which the nation's AIDS caseload is likely to double and early interventions are likely to further increase demand for care services.

The combination of programs funded by HRSA has created a necessary, although seriously underfunded, service mix to meet the growing needs for home and community based social and health care supports for people living with HIV. The mix must be sustained and expanded, especially in those jurisdictions hardest hit by the epidemic if the collapse of targeted health care delivery systems is to be avoided. The Coalition believes that more than $500 million will be needed to accommodate the considerably increased burden that will be experienced by state and local health care agencies, community based service providers, hospitals, and other primary care settings.

Over the last year, numerous sources -- ranging from academia and the press to state and local public health officials and care providers -- have described the increasingly devastating impact HIV-related care demands have had on existing systems of providing health care for the poor. Hospital gridlock and serious under-reimbursement are critical problems particularly in the highest incidence areas; community health centers and other primary care settings are overcrowded with HIV patients requiring intensive intervention; and community based organizations, which formerly kept so many individuals out of expensive hospital settings by providing critical home and community based services, are having to turn people away as their resources are stretched to the limit.

To address this crisis, the NORA Coalition calls for the immediate establishment of a $300 million impact aid program to rapidly channel necessary resources to those communities that have been most affected by HIV. Consistent with other Federal emergency programs, the resources should be targeted to local jurisdictions who will be able to allocate the funds flexibly based on priorities developed through an advisory process involving provider and consumer representatives. We expect that funds would be used to provide for the development of a range of out-of-hospital social and health care supports that would result in decreased inappropriate use of acute care settings.

The NORA Coalition also supports the expansion of the following existing HRSA programs:

o We support the doubling of funds for the adult and pediatric Health Care Demonstration programs to $68.4 million. These activities have been critical to the planning and development of consortia-based models of care that have provided a continuum of support to people with HIV disease. These consortia have emphasized more cost effective, non-hospital based care. Allocation of resources to adult and pediatric efforts should reflect incidence and demographic trends.

o The efforts of the adult and pediatric Health Care Demonstration grants are about to be supplemented by the release of new Home Health and Subacute Care grants in FY 1990. These initiatives, are an important recognition that out-of-hospital care options are a necessary component of a cost-effective continuum of care in all jurisdictions, not just those with highest incidence. The Administration has recommended defunding these programs in FY 1991. The NORA Coalition recommends funding these initiatives at $30.3 million in 1991, or $10 million above the FY 1990 level.

o During the last three years, HRSA has provided funds to states to subsidize the purchase of critical life-prolonging drugs for individuals who are otherwise uninsured or underinsured. This year, the Public Health Service announced research findings supporting expanded prophylactic use of AZT and aerosolized pentamidine. Both of these drugs have been shown to prolong life and improve an individual's health status during asymptomatic stages of the disease, often keeping patients more productive and diminishing use of acute care and other primary care services. Now is the time to expand AIDS Drug Assistance Program, not discontinue it as the President proposes. NORA therefore recommends $50 million for continuation of this program.

o Critical to the planning efforts of middle and lower incidence jurisdictions was the funding in FY 1989 of the state planning grants. The $4 million allocated that year has served to promote integrated planning efforts so that future HIV-related care needs can be anticipated before growing caseloads overwhelm primary health and social service programs. NORA recommends refunding the program in 1991 at a level of $10 million.

o As the primary care providers for many very low income individuals, the Community and Migrant Health Centers have increasingly provided services to those affected by HIV. NORA recommends expansion of the 1990 targeted funding of $10 million for the CHCs' AIDS efforts to $25 million, rather than the $13.3 million in the Administration's request. C/MHCs would also be eligible for funds under the impact aid proposal discussed above. NORA also recommends that HRSA facilitate adequate data collection efforts to assure that increasing case mixes and service needs can be adequately anticipated. NORA also urges closer collaboration between the CHCs and the NIH's clinical trials to assure better access to these trials for low-income individuals.

o A critical component of assuring the availability of subacute care settings is access to resources for facility renovations. The Administration has proposed reducing the existing AIDS Facilities Renovation grants to $4.1 million in 1991, from the current $4.2 million. NORA recommends an increase to $10 million for this program. We urge that the program permit use of these funds for residential settings for individuals with severely compromised health where health care services are provided, but not necessarily directly by the residential services operator. These funds should not be used for the renovation of inpatient hospital or skilled nursing facilities for which other capital construction or renovation dollars are available.

o NORA supports $10 million for funding of health professions faculty training, clinical skills development, and curriculum enhancement regarding AIDS, as authorized under the Health Professions Training Act under P.L. 100-607 in 1988. Current funding to implement AIDS-related curricula in health professions schools is extremely limited. Funding of this program will allow future health care providers to receive the proper training and understanding necessary to treat AIDS patients.

o The Administration has proposed a 45 percent increase to $21 million in the resources available for the training of health care personnel at the regional AIDS Education and Training Centers. NORA proposes instead only a $2 million increase, bringing FY 1991 funding to $16.5 million. In addition, NORA strongly urges that HRSA require the linkage of the ETCs' efforts to community based AIDS primary health and social service efforts, including the HRSA Health Care Demonstration Grants program, and especially to general health providers who will increasingly be providing services to individuals with HIV. HRSA should also compile a report for Congress regarding the target service populations being served, the education models and curricula that are being developed, the potential for replicability, and the extent to which these services are being provided within community based settings.

o The NORA coalition also supports $5 million for oral health care costs, as authorized in the HOPE legislation in 1988 (P.L. 100-607). Many of the first physical manifestations of HIV infection are in the oral cavity; therefore, a dentist is often the first diagnostician to see the patient. HIV infected patients are susceptible to severe oral infections that often compromise their medical condition. A recent study concluded that oral health care is often an overlooked and unmet need of AIDS patients.

NATIONAL INSTITUTES OF HEALTH

1991 NORA Recommendation:	*$950,000,000*
1991 President's Request:	*$800,164,000*
1990 Appropriation:	*$743,532,000*

Over the last few years, there have been dramatic advances in the treatments available for persons with HIV infection and disease. These treatments are prolonging life expectancy and improving the quality of life as well. These advances have occurred as a result of a substantial investment of research dollars that must continue if more progress is to be made. While the treatments now available are important, they have not accomplished a cure or made HIV infection a chronic condition. But they do show that these are attainable goals.

Substantially more than $950 million could be spent on quality and important AIDS research. However, the Coalition is mindful of the tight fiscal constraints facing all biomedical and behavioral research. We believe that while $950 million for AIDS may be the appropriate portion of the overall NIH budget, we support substantially larger appropriations for all NIH programs, including AIDS, and are very concerned with the low growth rate for NIH generally. If the Human Genome Program, which grows by 81.4 percent or $48.5 million in FY 91, is excluded from calculations, NIH funding grows by only 4 percent, not even keeping up with inflation in the biomedical field.

The NORA Coalition is deeply concerned that the President's requested increase in funding will not permit the research community to advance the fight against AIDS sufficiently in fiscal year 1991. Many of the NIH programs are funded through multi-year contracts and grants whose negotiation has assumed substantial growth in the out years. All the institutes have had to "downward negotiate" both competing and non-competing grants in FY 1990. NIAID, for example, has reduced AIDS and non-AIDS grants by 14 percent in FY 1990, with the exception of the AIDS Clinical Trial Groups, which are being cut by six percent. With even smaller growth in the President's budget in 1991, we fear more severe cuts will be required -- or no new initiatives will be fundable, even if new avenues of research open up.

In this context, we believe the $150 million recommendation above the President's request will still require some very difficult decision making regarding priorities in the NIH AIDS research program. We urge that highest priority be given to treatments, particularly the much neglected research into opportunistic infections that actually cause illness and death among persons with HIV infection. These have been given very belated attention, and we urge that they be given the highest priority in fiscal year 1991 allocations.

We support a substantial increase in funding for the NIAID's Community Program in Clinical Research on AIDS (CPCRA). Drugs to treat OIs have not received as much interest from the pharmaceutical industry and the academic scientific community as anti-retroviral treatments. For example, the AIDS Clinical Trial Groups, the centerpiece of the NIH's clinical research on AIDS, have been reluctant to take on research into opportunistic infections. On the other hand, much of the dramatic progress that has occurred around OIs has taken place through community based research. Since progress in this area will result in the quickest short-term gains for persons with AIDS, and the per-patient cost of community research is lower than in the current ACTG structure, expansion of CPCRA is a wise investment. CPCRA was unable to fund many highly rated proposals in its initial round of awards and we support the NIAID's plans to increase the number of awards in fiscal year 1991. The President's budget does not permit the level of expansion deemed necessary by the agency, and we support an additional $13 million for this program.

Given the late start that NIH efforts on opportunistic infections have received, we are particularly hopeful that there will be substantial expansion of the National Cooperative Drug Discovery Group Program for the Treatment of Opportunistic Infections. We are concerned that the President's request does not provide sufficient resources for the NCDDG-OI to assure that this program move as rapidly as possible in gaining the capacity already in place for anti-retroviral drug development, nor does it provide adequate related programming in toxicology support, chemical and pharmaceutical support, and development of animal models. We support the additional $10 million deemed necessary in the professional judgment of the agency.

Development of treatments for HIV itself must also continue. We are concerned that one of the most promising programs, NCI's preclinical drug screening project, is funded at such a low level that it only has the capacity to develop three or four compounds a year. If more are discovered, the NCI budget justifications warn that licensing arrangements will have to be made with the private sector to continue research and development. We believe that sufficient flexibility should be given the NIH budget to permit NCI and NIAID to move forward without having to be totally dependent on private sector interest or initiative.

Continued growth in government funded clinical trials is necessary to support study of both the expanded number of possible therapies and the combination therapies that are being developed. Indeed, comparison and combination trials of drugs produced by different manufacturers may only be possible under government auspices. This requires adequate support for both the ACTG and CPCRA systems. We support an additional $9 million for the ACTG program, as deemed necessary in the professional judgment of the agency.

The continued growth in pediatric and adolescent AIDS cases and the special research questions associated with treating pediatric AIDS and conducting trials with pregnant women demand greater attention from the three NIH institutes working on pediatric AIDS: NCI, NICHD, and NIAID. The delays in assessing the value of AZT for children, for example, point to both management and fiscal deficiencies in the pediatric AIDS research program. We support an additional $23.3 million for pediatric trials at the NIH.

The Coalition supports greater coordination of comparable AIDS research efforts. For example, the integration of the pediatric clinical trials conducted by NICHD and NIAID are important to assure coordination of research and to be more cost effective. We hope that similar demands will be made on the AIDS Clinical Trial Groups, which represents the overwhelming portion of clinical research funding by the NIH. Several studies and hearings have shown tremendous discrepancies in productivity among the sites funded. Many of the ACTGs are up for recompetition in fiscal year 1991, and we see this as a potential source of tighter fiscal control.

While we acknowledge the NIH for its efforts to be more inclusive of all populations affected by HIV in its clinical trials, we continue to be concerned that women, minorities, and substance abusers remain under-represented. The CPCRA has been particularly successful in this regard and we urge that in reviewing the ACTGs for renewal that they be held to a similar standard. Trials of pregnant women and active drug users, for example, while rejected in the past must be part of the study of HIV if effective treatments and cures are to be found for all affected by AIDS. In addition, NIH should be urged to collaborate with HRSA-funded AIDS service grants and community health centers to improve access to clinical trials by underserved populations.

We believe that the NIH has seriously neglected its responsibility to understand all aspects of the AIDS medical crisis by providing only marginal resources for behavioral research efforts. These should be substantially increased and more advantage should be taken of integrating behavioral research with the biomedical research already under way (such as incorporating behavioral research issues with populations already included in clinical trials of drugs).

AGENCY FOR HEALTH CARE POLICY AND RESEARCH

1991 NORA Recommendation:	*$10,505,000*
1991 President's Request:	*$10,505,000*
1990 Appropriation:	*$ 8,474,000*

While a relatively small portion of the PHS's AIDS budget, the health care research conducted by this agency is critical to planning and understanding of the scope of the HIV epidemic. The NORA Coalition is very supportive of all efforts to define the costs associated with HIV-related care and the impact of various medical and care-related advances. We hope the results of this research will be given greater attention by the political decision makers within the Administration, who have often ignored the economic impact studies of HIV on our nation's health care system.

OFFICE OF THE ASSISTANT SECRETARY FOR HEALTH

1991 NORA Recommendation:	*$8,523,000*
1991 President's Request:	*$8,523,000*
1990 Appropriation:	*$6,439,000*

The funds appropriated to the OASH are to support the work of the National AIDS Program Office ($3.9 million) and the HIV-related work of the Office of Minority Health ($4.6 million).

The coordination and leadership roles of NAPO are important for an integrated and non-duplicative national AIDS program. We hope that as NAPO becomes a more established arm of the AIDS effort that it will have the capacity and authority to develop a true national AIDS agenda and that it will not become enmeshed in bureaucratic details of individual agencies.

The work of the Office of Minority Health brings an important perspective to AIDS prevention efforts as they affect minority communities. Given that the bulk of minority education efforts are funded through the Centers for Disease Control, close coordination and care that duplication is avoided are necessary.

FOOD AND DRUG ADMINISTRATION

1991 NORA Recommendation:	*$71,000,000*
1991 President's Request:	*$63,236,000*
1990 Appropriation:	*$56,220,000*

While not part of the Labor-HHS appropriations bill, the work of the FDA, as part of the Public Health Service, is obviously a critical component of the fight against AIDS. FDA, perhaps more than any other agency involved with AIDS, has been crippled by space and staffing shortages that have seriously delayed the review of promising AIDS therapies. Dramatic progress has been made in this regard for AIDS drugs, but similar movement has not been as apparent for other diseases.

The NORA Coalition endorses the overall FDA recommendations of the FDA Council. Included in those recommendations are additional funding for the AIDS research building on the NIH campus and training of AIDS researchers. We are especially supportive of the expanded computerization of the drug approval process. We also support $10 million for expansion of the discretionary grant program under the Orphan Drug Act.

We join the FDA Council in urging that the FDA's activities be funded out of general revenues, and that growth in FDA staff and programs not be dependent on the implementation of user fees, as is suggested in the President's budget. If the need for these expanded services is there, and we believe it is, they should be implemented and not side-tracked by the debate over user fees.

OTHER HHS PROGRAMS

National Commission on AIDS

We endorse the President's request of $3 million for funding of the National Commission on AIDS. The Commission has begun a vital assessment of the nation's AIDS response and will, in its second year, offer major recommendations for implementing a comprehensive response to this health crisis.

Office of Human Development Services (OHDS)

Within the Administration for Children, Youth, and Families, we support additional funding for three programs that target youth at risk to HIV infection. We support $35 million in funding for the Runaway and Homeless Youth program, as compared to the President's request for level funding at $28.8 million. This program funds nearly 350 community-based centers that provide short-term shelter and other crisis intervention services to help reunite youth with their families. It also supports regional coordination of services, national hotlines, and discretionary grants. Reportedly, at least 3,000 young people are turned away from these shelters each year because there are not enough beds.

Life on the streets increases the chances for HIV infection as teens, lacking skills, education, and experience, often practice "survival sex" to meet basic needs of food and shelter, and use drugs to escape the harsh reality of street life. While these funds are not directly used for AIDS, they address the underlying causes of risky behavior among disenfranchised adolescents. These shelters are often the only organizations in their cities and communities that are currently housing minors who are HIV-infected; in addition, many are instituting HIV-prevention programs.

We also support $15 million for the Transitional Living Grant Program for Homeless Youth, as opposed to the President's request for level funding at $9.867 million. This program is designed to provide residential and other services to homeless youth "to promote a transition to self-sufficient living and to prevent long-term dependency on social services." This program also attempts to keep young people off the streets, thus ameliorating many of the conditions that contribute to HIV transmission.

We urge $20 million for the Drug Abuse Prevention Program for Runaway and Homeless Youth, as compared to the President's request for level funding at $14.8 million. This program supports community efforts to prevent drug use and to provide early intervention services to high-risk youth. Again, the emphasis is on deterring young people from practices that can have devastating health consequences, including the transmission of HIV.

Senator Inouye. I thank you very much, Ms. McGuire.

Ms. Vaid?

STATEMENT OF URVASHI VAID

Ms. Vaid. Thank you, Mr. Chairman.

My name is Urvashi Vaid, executive director of the National Gay and Lesbian Task Force, which is the oldest national gay and lesbian political organization in the country, representing nearly 20,000 members.

The National Great Gay and Lesbian Task Force also cochairs the national organizations responding to AIDS, and we are here in that capacity. This marks the seventh year we have been before this subcommittee to support increases in AIDS-related appropriations.

At the outset, Mr. Chairman, I would like to thank you and your colleagues for the strong leadership you have provided to meet the challenges presented by this deadly and relentless epidemic. I particularly want to thank and take note of your leadership on behalf of the gay and lesbian community with your support of the Federal civil rights bill and your support on hate crimes, issues not before this committee, but we really appreciate your courage and support.

Your courageous leadership is needed now more than ever, as Ms. McGuire pointed out, to ensure that the fiscal exigencies of the day take into account the fact that the AIDS epidemic is far from over.

The National Gay and Lesbian Task Force strongly supports the full budget recommendation submitted to you today by the national organizations responding to AIDS. The NORA budget contains very specific and we believe reasonable justifications for increases to the current level of Labor-HHS appropriations. I would like to focus on the continuing and expanding prevention needs associated with AIDS and to highlight the NORA documents requests for additional funding for the centers for disease control and the Alcohol, Drug Abuse, and Mental Health Administration.

In the NORA document we recommend a $376 million increase over the President's CDC request. This increase would focus on AIDS counseling, testing, and prevention efforts. We specifically support $100 million increase in funds for community-based AIDS prevention programs. Because we still do not have a vaccine or a cure for this disease, prevention remains the best method available to us to fight the spread of HIV infection.

As you know the models for the prevention of HIV developed in the gay community with belated assistance from the Federal Government have worked. The NORA budget request reflects the continuing and expanded need for HIV prevention efforts to be targeted to the growing number of communities affected by AIDS, communities which include gay and bisexual men, but also include heterosexual women, racial minorities, adolescents, young adults in college, and IV drug users.

A great deal of attention has been given in the media to the growing epidemic of AIDS among IV drug users and their sexual partners. The NORA request supports the allocation of additional resources to reach those communities. Community-based education has worked, and we need to expand those models that have worked in the gay and bisexual mens community to replicate them in other communities in order to stop the spread of AIDS.

Another aspect of the ongoing prevention strategy is the reenforcement of behavior change. Education to change sexual behavior or drug use behavior cannot be a one-shot venture. It needs to be sustained and it needs to be reinforced. And that is why we support efforts to continue funding that education.

With regard to ADAMHA, the Alcohol, Drug Abuse, and Mental Health Administration, the NORA coalition seeks a $94 million increase over the President's request. We are particularly supportive of this important agency's efforts to do research into behavior change in order to gain a better understanding of how we can communicate the AIDS prevention message better. ADAMHA has also developed some very successful outreach demonstration programs for IV drug users and substance abusers. And we encourage and support their expansion.

And while the war against drugs is not a part of the AIDS budget, it bears stating that there is a critical need to expand the funds available for drug treatment slots. Providing treatment on demand is recommended by former President Reagan's commission in the HIV epidemic would have a significant impact on controlling the spread of AIDS and HIV.

PREPARED STATEMENT

In conclusion, Mr. Chairman, I want to commend you again and your colleagues for your commitment to fighting AIDS. We in the gay and lesbian community and NORA stand ready to work with you in every way possible to bring about an end to this crisis.

[The statement follows:]

STATEMENT OF URVASHI VAID

Mr. Chairman, I am Urvashi Vaid, executive director of the National Gay & Lesbian Task Force, the oldest national gay and lesbian political organization, representing nearly 20,000 members. NGLTF also cochairs the Housing Task Force of the National Organizations Responding to AIDS (NORA). This marks the seventh year the National Gay & Lesbian Task Force has come before this subcommittee to support increases in AIDS-related appropriations.

At the outset, Mr. Chairman, I would like to thank you and this subcommittee for the strong and invaluable leadership you have provided to meet the challenges presented by this deadly and relentless epidemic. We work very closely with gay and lesbian and AIDS activists in Iowa, and note they have been impressed with the leadership you have provided on this issue. Your courageous leadership is needed now more than ever to insure that the fiscal exigencies of the day take into account the fact that the AIDS epidemic is, sadly, far from over.

NGLTF strongly supports the budget recommendations submitted to you today by the National Organizations Responding to AIDS (NORA) coalition. The NORA budget document overall contains our reasonable and specific justifications for increases in the current level of Labor-HHS AIDS appropriations to a 1991 level of $2.88 billion. In my testimony this morning, Mr. Chairman, I would like to focus on the continuing and expanding prevention needs associated with this disease, and to highlight the NORA document's request for additional funding for the Alcohol, Drug Abuse and Mental Health Administration (ADAMHA) and the Centers for Disease Control (CDC).

We support the NORA recommendation for a $376 million increase over the President's request in AIDS counseling, testing and prevention efforts conducted by the CDC. We support specifically, $100 million in funds for community based AIDS prevention programs. Because we still do not have a vaccine or cure for this disease, prevention remains the best method available to us to fight the spread of HIV infection. As you know, the models for the prevention of HIV were developed in the gay community with belated assistance from the federal government. The NORA budget request reflects the continuing and expanded need for HIV prevention efforts in a growing number of communities, including, among gay and bisexual men, heterosexual women, racial minorities, adolescents, and IV drug users.

A great deal of attention has been given in the media to the growing epidemic of AIDS among IV drug users and their sexual partners. The NORA request supports the allocation of additional resources to reach those communities. Based on the clearly demonstrated success of community based models to educate and prevent HIV transmission in the gay and bisexual male communities, we strongly support the replication of these community based prevention efforts to reach the new constituencies confronting AIDS.

Another aspect of an ongoing prevention strategy is the reinforcement of behavior change. Education to change sexual behavior cannot be a one-shot venture—it needs to be a sustained process which reinforces the dramatic progress we have achieved. And our educational efforts must be expanded to achieve these life-saving behavior changes in low incidence communities.

With regard to ADAMHA, the NORA coalition seeks a $94 million increase over the President's request. We are particularly supportive of expanded efforts within ADAMHA to fund research into behavior change in order to gain a better understanding of how to communicate the AIDS prevention message. ADAMHA has developed some very successful outreach demonstration programs for IV drug users and substance abusers and we encourage their expansion.

And, while the war against drugs is not a part of the AIDS budget, it bears stating that there is a critical need to expand the funds available for drug treatment slots. Providing treatment on demand, as recommended by President Reagan's Commission on the HIV Epidemic, would have a significant impact on controlling the spread of AIDS and HIV.

In conclusion, Mr. Chairman, I want to commend you and your colleagues for your commitment to fighting AIDS. We in the gay and lesbian community stand ready to work with you in every way possible to bring about an end to this devastating crisis. Thank you.

Senator INOUYE. I thank you very much.

Ms. McGuire, in your presentation you stated that the caseload has increased?

Ms. MCGUIRE. Substantially. And I recognize that the information that you are hearing in the media is very conflictual around that.

And I would point out first of all that part of what we are experiencing in terms of caseload enumeration has to do with the fact that the early modeling about the numbers of individuals that were actually infected did not quite exactly represent it.

So there is some adjustment that is going on. But the adjustment downward is very minimal in terms of overall projection. The increase in caseload is very significant. We were at a 100,000 in July/August of last year before we began this current fiscal year. It took us 9 years to get there. We know we will be at 200,000 by the end of the fiscal year you are going to fund. That is a doubling of the impact of very sick people on very diverse jurisdictions all the way around the country.

And while there are some States that are clearly lower in their incidence factors, there are no States that are unaffected. And many of those States with lower overall numbers have very minimal health resources. And so that a relative impact of a deadly disease in the context of their constraint to health systems is extremely significant.

I think we have been quite worried with the increases that we have been seeing in the State of Hawaii. I think there are many factors that are associated with that. But I think that you have a situation there where you do not have a health structure that is going to be able to sustain the impact of the disease.

So I think that part of what we are talking about is that there has to be a comprehensive agenda. And yes, New York and California figure disproportionately. And in that context, I think they deserve the kind of relief that a disaster recommends. But there is no jurisdiction that can get away and can do without the planning for the resources for care.

Senator INOUYE. You spoke enthusiastically about prevention and education. Do we have any evidence to indicate that, as you say, these programs are working?

Ms. VAID. Yes, sir; we do. There is significant evidence that AIDS education and prevention efforts are working. They have changed the behavior in the gay community, where they have been the most prevalent. And we need to——

Senator INOUYE. Do you have studies?

Ms. VAID. What we are saying in our budget document is that we need to expand those efforts to the other communities where education and prevention messages have just begun to go out.

Senator INOUYE. Do you have evidence or statistics to indicate that it is working?

Ms. MCGUIRE. We have some—you know, I mean, obviously one of the difficulties with something that has expanded so fast is that it has taken a while to get the quantitative evidence that we need. But there is some very good information that the American Psychological Association among others has not brought together in terms of a quantitative analysis. And we can provide that to your office.

Senator INOUYE. I would appreciate that. Because that is what we will need to convince our colleagues that it is money well spent.

Ms. MCGUIRE. I would point out to you that the expansion that Urvashi was talking about through the Centers for Disease Control also includes expanded dollars and resources for testing and counseling, as well as for early intervention for individuals who are not ensured. And the importance of that component is that there are not the resources right now to respond to the demand that will be predicated as people become more understanding of the fact that there is something they could do about this disease.

And so we need to—some of what we are looking for in terms of the expansion is in addition to the prevention activities. There is also some early evidence of the activities that have taken place within the drug using community and with communities of people of color that are starting to evidence some good quantifiable information, and so these will be sent to your office.

Senator INOUYE. I thank you ladies very much.

Ms. MCGUIRE. Thank you.

Ms. VAID. Thank you.

STATEMENT OF ARLENE PESSAR, EXECUTIVE DIRECTOR, DYSTROPHIC EPIDERMOLYSIS BULLOSA RESEARCH ASSOCIATION

Senator INOUYE. And now we have the executive director of the Dystrophic Epidermolysis Bullosa Research Association, Ms. Arlene Pessar.

Ms. PESSAR. This is Estelle Larson of Silver Spring, MD. Mrs. Larson's son died of epidermolysis bullosa a couple of years ago.

I must congratulate you on the pronunciation. It is the first time that I have heard somebody pronounce it correctly. My hat is off to you.

Senator INOUYE. I practiced.

Ms. PESSAR. It is good to know. Well, if you think it is difficult to pronounce, it is a heck of a lot harder to live with.

I am Arlene Pessar. I am the founder and executive director of DEBRA of America. This is the 10th year we have come before this committee. And I am always grateful that we have the opportunity to do so. My son Eric usually accompanies me to these hearings. I am sad to report now that EB has now taken its toll on Eric's life, and this year he is much too weak to travel with me. He does send his greetings, however, and hopes you will continue your strong support for increased funds for EB research.

As you may be aware, 10 years ago I founded DEBRA of America to offer support to other parents and to encourage research on this devastating and debilitating disease. At that time little was known about EB, and the Federal Government was virtually funding no research grants.

Looking back it is hard to believe that so much has been accomplished over the last 10 years. And right now DEBRA is planning its 10th-year anniversary celebration. We are very thankful to this committee and its members for supporting us in our work, and in one of our most important goals to increase research on EB and to encourage the establishment of EB research centers.

The support of EB centers by the National Institutes of Health is essential if we are to move forward in our quest for identifying the causes, isolating the genes, and ultimately developing therapies to treat and cure this terrible disease. In my written statement I have summarized some of the areas presently being funded by the National Institute of Arthritis, Musculoskeletal and Skin Diseases.

The news is good. But yet, I am worried about the future. Since its establishment as a separate Institute in 1986 this Institute has not been adequately funded. Each year fewer and fewer approved grants are funded. And the lack of support is discouraging young people from pursuing careers in basic science. I am also concerned that opportunities will be lost if this Institute does not have sufficient funds to renew the contract for the national EB registry.

The registry has presently enrolled over 1,200 patients so far, and has initiated clinical studies on a variety of problems, such as wound healing, gene mapping, skin cancer, and artificial skin replacements. And what about the plans to establish research centers?

It is clear that this committee recognizes the importance of EB centers as illustrated in the report language on EB for fiscal years 1989 and 1990. Unfortunately, without additional funds this Institute will not be able to support any such centers.

It is for all these reasons and a whole host of others that I respectfully urge this committee to add $50 million to the 1991 budget for the National Institute of Arthritis, Musculoskeletal and Skin Diseases. Without this kind of increase, there will be no new clinical trials, no new training grants, no new centers, and the percentage of approved research projects will continue to decline.

Mr. Chairman, as DEBRA celebrates 10 years of service and ushers in a new decade of hope and progress, we are writing the history of EB. It salutes thousands of EB patients and families who have helped to build our organization. It contains the names of a few scientists who have dedicated their lives to finding the cure for this terrible disease. And it recognizes the Congress and members of this committee for the role they have played toward eradicating this killer disease.

PREPARED STATEMENT

For our part, we continue to provide support, information and assistance to help our families live fuller and more productive lives. But there are some things we cannot do. And it is for these things that we must come to you, to ask you to continue to build and strengthen your investment in EB research through additional funding for the National Institute of Arthritis, Musculoskeletal and Skin Diseases.

Your support has made a difference. I beg you to continue to make a difference.

Thank you.

[The statement follows:]

STATEMENT OF ARLENE PESSAR

Mr. Chairman, members of the subcommittee:

I am Arlene Pessar, founder and executive director of the Dystrophic Epidermolysis Bullosa Research Association of America (D.E.B.R.A.). I have just completed a three-year term as a member of the Advisory Council of the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS), and serve on the Board of Directors of the National Organization for Rare Disorders (NORD), and the Coalition of Patient Advocates for Skin Disease Research, and the Coalition for Heritable Disorders of the Connective Tissue.

This is the tenth year I have come before this committee and I thank you for this opportunity. I am here today to speak on behalf of millions of Americans who suffer from skin diseases, many of which are "orphan" diseases, and diseases of the connective tissue, which are debilitating and very often fatal. Mostly I am here to represent more than 50,000 infants, young children and adults who suffer from Epidermolysis Bullosa (EB), including my own son, Eric Lopez, who has lived with this devastating disease his entire life. Eric is now 19 years, and last year he testified before the committee.

Epidermolysis bullosa (EB) is a group of inherited diseases in which the skin and mucous membranes are so fragile that the slightest touch may cause painful blistering and destruction of the body, outside and inside. In its severest form, children blister at the slightest touch and develop deformities that cause their fingers and toes to fuse together and their throats to close preventing them from eating. Many of these children suffer from malnutrition and chronic anemia. Some have difficulty breathing because of blistering in their nasal passages and larynx. Eventually, many people with EB die as a result of overwhelming infections, secondary complications of kidney or heart failure, or aggressive skin cancers.

Treatment for EB is only symptomatic because the underlying defects that lead to the disease are not well understood. The medical costs per patient are enormous and can average as much as $50,000 per person annually. Many families do not have health insurance and are forced to on public assistance and medicaid. Others publicize their plight in the media or ask their local churches and civic groups to help them meet the cost of mounting medical bills.

D.E.B.R.A. of America was founded in 1980 to offer support to families and provide information and public awareness. This year D.E.B.R.A. is celebrating its tenth anniversary. Looking back it's hard to believe that so much has been accomplished to help those who live with this devastating genetic disease.

We are thankful to the members of this committee because you have supported us in our work and our most important goal -- to increase research on EB and to encourage the establishment of specialized centers of research. The creation of skin disease centers is a necessary step if we are to move forward in our quest for improving diagnosis, identifying the defective genes, and ultimately develop new therapies to treat and cure these terrible diseases.

I am pleased to report that the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) is presently supporting several research projects on EB, as well as the National EB Registry. As a result of this work, there has been a great deal of progress in understanding some of the basic defects in EB. By studying the molecular structure of the basement membrane zone, the area between the outer and inner layers of the skin, researchers have identified a specific protein called Type VII collagen that is missing in the skin of some EB patients.

Increased knowledge about the clinical and microscopic features has also led to the identification of more than 20 different subtypes of EB. Although this information may not be considered as a major breakthrough, it is very important to help inform new parents about the inheritance patterns of the disease and educate them about specific symptoms and some preventive measures.

Another exciting program is the National EB Registry. Several preliminary studies are underway utilizing the data from the registry and to conduct gene-mapping studies. The registry has opened up new avenues to facilitate research, including clinical trials, because there are now large numbers of patients who are willing and available to participate in different research projects.

Yet, despite all this wonderful news, I am worried about future progress. Since its establishment as a separate institute in 1987, NIAMS has not been adequately funded. Over 83% of approved NIAMS research grants go unfunded. Furthermore, the lack of resources for career development awards and training fellowships for NIH as a whole, and specifically for the NIAMS, is discouraging young people from pursuing careers in research.

And what about the opportunities and hope that the National EB Registry holds? We need to be assured that the NIAMS will have sufficient funds to renew the contract for the registry.

My concerns also include support for research centers. It is clear that this committee recognizes the importance of research centers. The report language on EB for fiscal year 1990 states, "the Committee continues to believe that specialized centers of research have proven to be a successful mechanism in addressing the multidisciplinary needs of other genetic diseases and encourages NIAMS to plan for the establishment of a limited number of these centers for EB and other castastrophic skin diseases." Unfortunately, because of inadequate funding, NIAMS has only been able to establish two core skin disease centers rather than the six that were mandated. At the present time, there are no plans to establish specialized centers of research.

It is for all the reasons I have just given that we strongly support the recommendations of the Coalition of Voluntary and Professional Associations Concerned with the Programs of the National Institute of Arthritis and Musculoskeletal and Skin Diseases and urge you to add $50 million to the FY 1991 budget for NIAMS. Without this additional support, there will be no new centers, no new clinical trials and fewer and fewer approved research grants will be funded.

As D.E.B.R.A. celebrates ten years of service and accomplishments, we are writing the history of EB. It salutes thousands of patients and families who have helped to build our organization. It contains the names of a few scientists who have dedicated their lives to finding a cure for this disease. And it recognizes the

Congress and members of this committee for the role they have played toward eradicating this dreaded disease.

For our part, we continue to work at providing support, information and assistance to our families. But there are things we cannot do. And it is for these things that we must come to you -- to ask you to continue to build and strengthen your investment in EB research through adeuate funding for the National Institute for Arthritis and Musculoskeletal and Skin Diseases.

Your support has made a difference. I urge you to continue to make a difference.

Thank you for giving me this opportunity to express my concerns.

Senator **Inouye**. How many clinical trials are now being held?

Ms. **Pessar**. At the present time I do not think any are funded through the National Institutes of Health. They are funding through private means and through portions of research grants of some of the investigators. I do not believe the National Institutes of Health is funding any clinical trials.

The FDA has recently—has completed a 5-year study, a multicenter study through its orphan product division, through its orphan division disease branch on the drug Dilantin. Unfortunately, this drug proved not to be helpful in this disease. Dilantin is used for epilepsy. But they found that in the basic work on EB that Dilantin may be helpful in controlling the blistering in some children with EB.

In the room here with me is the president of the American Academy of Dermatology. Now he may have some other—Dr. Lowell Goldsmith—he might have some more information on some of these clinical trials that are going on that I am not even aware of.

Senator **Inouye**. Doctor, would you like to enlighten us?

Dr. **Goldsmith**. There are clinical trials which are in the expanded $50 million budget, including some specific trials using some new growth factors in EB. But there are currently no funded trials.

Senator **Inouye**. You spoke 1,200 of EB patients who have been registered. Approximately, how many are there in the United States?

Ms. **Pessar**. We think there are as many as 50,000 children with this disease throughout the United States. And we know of several families with little children in Hawaii.

Senator **Inouye**. We will do our best to get you——

Ms. **Pessar**. That figure may be low. There are different forms of the disease. And in many families, it is inherited dominantly. So we think there are as many families that may have 30 and 40, you know, relatives in the family. And many of these families are not reported into the registry, because it is minor blistering, just from picking up a glass of water or just mowing your lawn would cause blisters.

So it is not severe enough, you know, to bring it to the attention of a physician, or they just kind of live on generation through generation. I think the 1,200 are the more severe forms of the disease that are being registered. Although we are trying to locate everybody throughout the country.

Senator INOUYE. We will do our best.

Ms. PESSAR. Thank you very much.

Senator INOUYE. And give our best to your son.

Ms. PESSAR. Thank you.

STATEMENT OF JUDITH HELLER, REPRESENTATIVE, INTERSTITIAL CYSTITIS ASSOCIATION

Senator INOUYE. Our next witness is Ms. Judith Heller representing the Interstitial Cystitis Association [ICA].

Ms. HELLER. Honorable chairman and committee members, thank you for allowing the ICA to represent our concerns to you today. Through your support over the last 4 years, we have made significant strides in our goal of finding a cure for IC.

As an IC victim, I have suffered with painful bladder problems since 1979. For 2 years I went from doctor to doctor seeking help. I volunteered to work for the ICA because it gave me crucial assistance when no one else was able to. The ICA was founded 6 years ago by IC victims.

Interstitial cystitis is a bladder disease which is too frequently ignored by the medical profession. It is an inflammatory disease affecting the bladder wall. The result in the patient is an intense, unrelenting excruciating pain accompanied by the constant need to urinate, sometimes as much as 60 times a day. Because of pain and frequency, many IC patients become totally housebound, unable to work or engage in ordinary activity.

An epidemiological study sponsored by the Urban Institute found that an estimated 450,000 people in the United States—mainly women—may suffer with IC and of those patients 50 percent are unable to work full time. The economic impact of the disease may be as high as $1.7 billion per annum.

The frustrating and painful journey toward diagnosis can take an average of 4½ years and five doctors. This disease continues to be misunderstood by the medical profession. Life with IC can be absolutely devastating. Intercourse is often impossible and suicide is a very serious problem.

Many of these victims cannot leave their homes for a short trip to the grocery store. IC victims are trapped in a body that is torturing them day and night with no hope for relief. There is no cure for interstitial cystitis and no effective treatments.

I appeal to you to continue your strong support for IC research. In last year's report you urged the NIDDK to explore the feasibility of establishing a national IC registry and issue an RFP for such a registry within available funds. Your previous years report contain similar language. Sadly, this has not happened. In fact, they have not even had a meeting to determine the feasibility of a register, even though the ICA offered to assist them in organizing such a meeting and did the necessary research for it.

Instead of working toward the establishment of a national IC registry NIDDK funds have been used toward a pilot data base project on IC. We are very concerned that this pilot data base project will further delay the establishment of a national IC registry.

In order to find a cure for IC we need to know more about the disease, how it manifests itself over time and what treatments are the most effective. A national registry would collect the necessary statistics needed to answer many important outstanding questions on IC.

We believe that the NIDDK has finally recognized the necessity for such a registry, but now they tell us they are unable to initiate one without a specific earmark of funds. It is also imperative that IC research be fiscally supported by the NIH. Only 2 IC projects were funded last year, even though 14 of the 15 projects received were approved with 6 receiving excellent scores.

There is a community of IC researchers that are ready, willing and keenly interested in conducting high quality IC research. RFA's and program announcements on IC are ineffective unless the NIDDK is willing to back these up with the sufficient level of funding.

The 5-year plan on IC was to outline programs that would make IC research a priority. But in reality IC research is only a very small part of the NIDDK urology budget and a disproportionate amount of the urology budget funds male urological problems.

Time is running out for many young women who are only beginning their careers and starting families. The older IC patient is forced to take early retirement, a retirement filled with pain and suffering, becoming a prisoner in her own home. Our lives depend on IC research and your support in funding them at the Federal level.

We, therefore, request the following: One, that IC be included in the Senate committee report. And that at least $2.5 million be earmarked specifically for the funding of IC research and for a national IC registry in fiscal year 1991. That a request for proposals be issued specifically for a national registry. And three, that the NIDDK issue an RFA specifically for IC in fiscal year 1991 and designate sufficient funds for that purpose.

Our need is great, but we are confident that with your help and with adequate funding for IC research through NIDDK the results will be no less than miraculous. As an IC victim, I know what it is like to endure chronic unrelenting pain. I represent those who are too ill to leave their homes and who cannot be here with us today.

Please help us to end our suffering. Please help us to find a cure for interstitial cystitis.

Thank you.

Senator **Inouye**. As you know the National Institute has spent less than one-third of the amount appropriated last year. And I am dismayed with that. We will personally get together with the Institute to tell them first to spend the money that we have appropriated. And second, at least read our report and our request and to assure them that we are not wasting our time writing these reports.

Ms. **Heller**. We appreciate that.

Senator **Inouye**. I can assure you that a national registry project will be carried out.

Ms. **Heller**. I thank you. That is very kind. Thank you.

Senator **Inouye**. I thank you very much.

STATEMENT OF LORRAINE JORDAN, DIRECTOR, EDUCATION AND RESEARCH, AMERICAN ASSOCIATION OF NURSE ANESTHETISTS

Senator **Inouye**. Our next witness represents the American Association of Nurse Anesthetists, Ms. Lorraine Jordan.

Ms. **Jordan**. Hello, Senator Inouye.

First of all before I even start I want to thank you and your staff for all your support. Pat, I appreciate everything you have done for us and the interest that you have shown in our cause and, what we want to do in the health care delivery system today.

I am Lorraine Jordan. I am a certified registered nurse anesthetist. I represent over 24,000 CRNA's in the United States. I am director of education and research for the American Association of Nurse Anesthetists.

I want to thank you for first of all supporting traineeships for nurse anesthetists, as well as startup and expansion cost for nursing anesthesia programs. All the money that we have received has been expended, and we have over 500 students under the traineeship program today.

The rest of the money we are presently negotiating with the division of nursing in regards to startup cost and faculty development. Most of all, though, the thing I want to really say thanks to is the congressional mandated manpower study, that hopefully you have received a copy of. If you have not, I can surely supply you with that.

The House of Representatives Appropriations Committee mandated that a study be done to identify the need and the manpower needs for nurse anesthetists in this country. The findings reveal that we need 25,000 nurse anesthetists today, an additional 6,000 that we have.

The study documents that there is a decrease in the number of nursing anesthesia programs for two reasons. Basically an increase in our standards to move to the graduate framework; decrease and that meant a closing of the hospital-based programs, as well as an increase in the anesthesiology residency programs. Therefore, that has limited access for us in the clinical arena.

There has also been a decrease in the number of students in the field and that is because of the limited spaces because of the lack of clinical access today.

CRNA's are a vital part of the health care system. We deliver all types of anesthetics during all types of surgical procedures. We are the sole anesthesia providers in 33 percent of the hospitals in this country. We administer over one-half the anesthetics in this country and 70 percent of the anesthetics in rural America.

Senator **Inouye**. I think you should repeat that again, because most physicians hate to admit that nurses provide most of the anesthetics in this Nation.

Ms. **Heller**. I would love to repeat that.

Over one-half of the anesthetics in this country are delivered by nurse anesthetists. We are the sole providers, or the only provider—anesthesia provider—in 33 percent of the hospitals in this country. And we provide over 70 percent of the anesthetics in rural America today.

Senator **Inouye**. It is about time you get treated like professionals.

Ms. **Heller**. Thank you.

Financial appropriations are essential to secure our nursing anesthesia programs in the future. Therefore, I am asking you to consider fully funding the programs presently intact at $1.8 million. I would like you to continue funding—fully funding—the traineeships at $800,000. And then the other $1 million to be presented to start up and expand our current programs.

PREPARED STATEMENT

Once again, I want to thank you for all your support. It has really been invaluable. And I have to say when we talk about individuals on the Hill, your name always pops up and it is always first. And I want to thank you for that.

I would like to formally ask you to consider my written testimony to be submitted for the record.

Senator **Inouye**. Your full statement will be part of the record.

[The statement follows:]

STATEMENT OF LORRAINE JORDAN

I welcome the opportunity to discuss with you the status of nurse anesthesia education today. My name is Lorraine Jordan and I have some good and bad news to report to you. I am a Certified Registered Nurse Anesthetist (CRNA) and Director of Education and Research at the American Association of Nurse Anesthetists (AANA). The good news results from the completion of a study of nurse anesthesia manpower needs in the United States. This study has quantified the need for CRNAs--one projection identifies the need for 35,433 CRNAs in the year 2010; an increase of 40 percent over the 25,287 needed in 1990. Several barriers to achieving such increases exist and I am hopeful that continued support from this Committee along with continued federal funding will assist in addressing these problems.

Background on Nurse Anesthesia

Over 23,000 CRNAs provide quality anesthesia care to more than 65 percent of all patients undergoing surgical or other medical intervention which necessitates the services of an anesthetist. In addition, CRNAs administer anesthesia for all types of surgical cases, from the simplest to the most complex. CRNAs are the sole anesthesia providers in approximately 33% of hospitals in the United States; many are in rural areas. CRNAs work in a variety of practice patterns--as hospital employees, as employees of physicians or physician groups, and as private contractors.

Supply of CRNAs

A study of nurse anesthesia manpower needs in the United States was requested by the House of Representatives appropriations committee (Report 100-689, p. 84). As a result, the National Center for Nursing Research entered into an agreement with the Division of Nursing to support the study and contracted with Health

Economics Research, Inc. The objective was to develop projections of the supply of and needs for certified registered nurse anesthetists and to assess the educational objectives for nurse anesthesia educational programs. AANA would be pleased to provide any interested Members or staff with a copy of this report. We are very appreciative of the funding that allowed for this report.

The study documents recent declines in the number of educational programs that prepare registered nurses to become anesthetists and the concomitant decrease in annual graduations of CRNAs. Historically, CRNAs have outnumbered anesthesiologists (MDAs). Twenty years ago there were about two CRNAs for every one anesthesiologist. However, a major shift has occurred in this balance. Today, the ratio is closer to 1.2 CRNAs to 1 MDA.

The leveling off in the number of CRNAs has been attributed to two waves of educational program closures. The first occurred during the latter part of the 1970s, when many of the smaller, hospital-based certificate programs closed as a result of the adoption of higher accreditation standards. Concurrently the profession adopted a goal supporting the premise that the education of nurse anesthetists should be at the post-baccalaureate level.

More recently, closures have been largely attributed to the denial of clinical access to nurse anesthesia education programs because of the increase in the number of anesthesiology resident positions. Anesthesiology has become increasingly more attractive to medical graduates for a variety of reasons. The competition for limited clinical placements has been fierce in some institutions. Both nurse anesthesia students and anesthesiology residents require the same type of clinical site and, in order to graduate, nurse anesthesia students are required to provide a minimum of 800 hours of anesthesia and participate in 450 cases. To address this problem our association has encouraged several initiatives

- opening of new schools of nurse anesthesia;
- expanding the capacity of existing programs by developing additional clinical affiliations; and,

- encouraging the development of cooperative educational ventures between universities and multiple clinical sites.

Authorization Legislation

Within the authorization in the Nursing Education Amendments of 1988 there are several major provisions pertinent to CRNAs. The provision to provide financial support to plan, develop and operate schools of nurse anesthesia was new in 1988. This provision expanded upon the traditional authority to fund traineeships programs for nurse anesthetists students and faculty. Traineeships are vital to this intense, non-stop 24 to 36 month education--which rarely allows time for students to work part-time. In addition, the traineeships enable needy students to graduate. This year approximately 600 students are receiving funding through the traineeship program. At the present time representatives from AANA are discussing with the Division of Nursing possible ways to utilize the funds appropriated last year to fund new educational programs and strengthen ongoing programs. We are confident that these funds will make a significant contribution to addressing this problem. Therefore, as you consider funding levels for 1991, **we are requesting an appropriation at the level of the full authorization--$1.8 million.** Within this account, we recommend that funding for nurse anesthetist traineeships be maintained a the current level. Our next priority is that any additional funds above and beyond funding for traineeships would be for the development of new educational programs or expansion of existing programs.

National Center for Nursing Research

As a member of the Nurses' Coalition for Legislative Action, we wholeheartedly support the recommended funding levels of the

Coalition--$42.5 million. This funding will allow for the initiation and enhancement of major research programs such as caregiving for older people, preventing low birthweight, prevention and care for HIV infection, and diagnosis and treatment of pressure sores. In addition, AANA is pleased to observe the growth of a cadre of nurse scientists which has been stimulated by the Center. Growth in the numbers of highly skilled scientists coupled with the rapid dissemination of the outcomes of nursing research will enhance the effectiveness of our care for patients.

Summary

The American Association of Nurse Anesthetists is very appreciative of the support which this Committee has demonstrated to the nursing community and specifically to CRNAs over the past several years. We believe the return on investment has been significant. A small, yet significant, upturn in admissions to schools of nursing has been observed. Patient care by nurses has been strengthened and the American public has the continued choice of a quality, cost-effective health providers. As we have indicated in this testimony, for certified registered nurse anesthetists the historical role as providers of anesthesia services is changing. Full funding of the nurse anesthesia provisions of the nursing education amendments will help to preserve the availability of this specialty nurse.

Senator INOUYE. Listening to your testimony, I am almost dismayed to tell you that if this were the defense account, you would get full funding without any hesitation, because there is a shortage of nurses in the military health delivery system. But here we will have a few problems, but I can assure you we will do our best.

Ms. HELLER. What can I do to move to the defense account?

Senator INOUYE. No; you do not want to get there. [Laughter.]

Ms. HELLER. Thank you.

Senator INOUYE. Thank you very much.

STATEMENT OF CHARLES FELTON, M.D., REPRESENTATIVE, INTERNATIONAL UNION AGAINST TUBERCULOSIS AND LUNG DISEASE

Senator INOUYE. Our next witness represents the International Union Against Tuberculosis and Lung Disease, Dr. Charles Felton.

Dr. FELTON. Thank you, sir.

It is indeed an honor and a pleasure to appear before you, Senator Inouye. I have been an admirer of yours for many, many years.

Mr. Chairman, members of the subcommittee, I am Dr. Charles Felton, clinical professor of medicine at the College of Physicians and Surgeons, Columbia University.

I am appearing today on behalf of the North American region of the International Union Against Tuberculosis and Lung Disease. The union was established in 1920 and has approximately 120 member countries, including the United States, represented here by the American Lung Association and its medical section, the Medical Thoracic Society.

I welcome this opportunity, sir, to support increased funding for the tuberculosis control efforts of the U.S. Public Health Service.

At the outset, Mr. Chairman, I would like to thank you for the subcommittee's continued support for the grants for preventive health projects for tuberculosis. This program was authorized or reauthorized in the last Congress. And an important new component was added to that authority, namely, a provision for research activity.

Recently the House Subcommittee on Health and Environment reported a bill which would provide further reauthorization of the program. The subcommittee spent considerable time addressing the critical program concerns raised in the strategic plan for the elimination of tuberculosis and the role of the project grant in this plan.

The IUAT recommends that the full authorized level of $36 million be appropriated for the tuberculosis project grants and that moneys be allocated through the set-aside for new research initiatives within the Centers for Disease Control and the National Institute for Allergy and Infectious Diseases.

It is estimated, sir, that worldwide each year 8 million new cases of tuberculosis occur and that 3 million people die because of this disease. It is estimated further that tuberculosis is responsible for approximately one-quarter of the preventable deaths in the world. It is one of the most prevalent infections in the world, and it is estimated that over one-half of the world's population is infected with the tubercle bacillus.

Although tuberculosis is a preventable and curable disease, it persists as a public health problem in the United States. Significant progress has been made by the U.S. Public Health Service since it was created in 1944, but much remains to be done, as evidenced by the fact that in 1988, 22,436 new cases were reported in this country.

An estimated 10 million Americans are currently infected with the tubercle bacillus—that is, with tuberculosis. And the majority of new cases occurs in the group. Based on data from the Centers for Disease Control, an estimated 15,000 excess cases occurred since the decline in the tuberculosis rate began in this country in 1979.

Today marked increase in tuberculosis in the United States occurs in certain specific populations: first of all, persons who are infected with the human imminodeficiency virus. HIV infection appears to increase the incidence of tuberculosis by causing immunal suppression which allows the latent tuberculous infection to progress on to clinical disease.

Among the minorities, nearly two-thirds of the cases now occur among racial and ethnic minorities. The case rate is consistently higher for nonwhites; 29 per 100,000 population of minorities compared to 5.6 per 100,000 in the white population in 1985. Over 84 percent of cases in nonwhites can be considered excess cases. Among children, 1,134 cases were reported in children under 15 years of age in 1988. More than 55 percent of cases in children in that year occurred in minority children.

Among the elderly, among all racial or ethnic groups in both sexes, the tuberculosis case rate is highest in the elderly. The majority of cases occur among the 95 percent of elderly persons who live in the community, although, the case rate is higher among the elderly living in the long-term care facilities.

And finally, among the foreign born tuberculosis is very common among immigrants, among refugees and migrant workers from high prevalence areas. In 1988 tuberculosis cases among the foreign born represented 22.9 percent of all cases reported in this country.

In 1987 the Advisory Committee for the Elimination of Tuberculosis was established within the Department of Health and Human Services to provide recommendations for the development of new technology. Application of prevention and control methods and management of State and local programs aimed at the elimination of tuberculosis.

The International Union Against Tuberculosis representative in this country—that is, the American Lung Association endorses the committee's recommendation that the United States establish the goal of tuberculosis elimination by the year 2010. And by that year that the case rate should be less than one case per 1 million population.

There is an interim target that the case rate of 3.5 per 100,000 be reached by the year 2000. Secretary of Health and Human Services Dr. Louis Sullivan has publicly endorsed the recommendations made by the advisory committee and has firmly reestablished the goal of tuberculosis elimination as administration policy. We applaud the commitment by the executive branch.

The project grant for tuberculosis for preventive health projects——

Senator INOUYE. I am just called back, because there is a vote in progress at this time. If you would just hang on for 6 minutes, I will be back.

Dr. FELTON. It would be an honor to wait for you, sir.

[A brief recess was taken.]

Senator INOUYE. Shall we resume?

Dr. FELTON. I thank you for indulgence, sir. And I am going to abstract from this, since my written statement has been submitted for the record. And expand the tuberculosis control program effort as recommended by the committee for the elimination of tuberculosis would not only prevent the majority of TB cases in the United States, but it would also save health care dollars, so that it would be cost effective.

It is estimated that without the implementation of the plan, elimination of tuberculosis will not be achieved until the year 2072. It is estimated that more than 664,000 cases of tuberculosis will be recorded in this period. And of these cases 64 percent would be preventable. In 1988 dollars, the prevention of more than 426,000 cases represents a savings of approximately $6.1 billion.

The union, therefore, recommends the subcommittee appropriate $36 million—the full authorized level—for tuberculosis project grants.

Now, it is paradoxical that we can talk about millions of tuberculosis cases and deaths worldwide in one paragraph and eliminating the disease in the next paragraph. But to eliminate TB in the United States and worldwide will require far more intensified and widespread use of existing prevention and control methods, the development of new treatments, diagnostic and prevention technologies and the rapid transmission of newly developed technologies to the field.

A key component for the plan of elimination of tuberculosis is the development and evaluation of new treatments and diagnostic and preventive technologies. Support for tuberculosis research initiatives outside of the Centers for Disease Control is concentrated within the National Institute of Allergy and Infectious Diseases.

The overall support within this Institute for research, specific to microbacterium tuberculosis has increased from $323,000 in fiscal year 1979 to $2.7 million in fiscal year 1989, funding 4 grants in one contract in 1979 and 19 grants in one contract in fiscal year 1989.

It is clear that there are other excellent applications not currently funded. Further, there is growing interest within the National Institute of Allergy and Infectious Diseases in initiating a program for the development of new drug therapies.

The International Union Against Tuberculosis recommends that $10 million be appropriated through the research set-aside for expanded tuberculosis research activity within the National Institute of Allergy and Infectious Diseases.

In summary, Mr. Chairman, tuberculosis is an infectious disease which can be transmitted without regard to geographic or governmental boundaries. It is a public health problem not only of national but, indeed, of international scope. Its prevention, control, and elimination require a strong Federal commitment and the recognition of the role of the United States as a leader in the fight against tuberculosis.

May I say, sir, that I am chief of chest diseases at the Harlem Hospital in the city of New York, which is a Columbia University affiliate. We have within that community 158 new cases of tuberculosis per 100,000 population per year. That is the highest rate—or highest incidence of tuberculosis—in the United States. It is the highest, to the best of my knowledge, in the Western Hemisphere.

PREPARED STATEMENT

This is a source of shame on the public health record of this country. I profit from the grants, from one of the grants, that gives us public health advisers to go out into the community as an outreach measure to bring in these patients. They are especially those poor unfortunate victims who are inflicted both with drug addiction and with the HIV infection.

The reauthorization of these grants are a very meaningful kind of program, especially, to the inner-city population of this country.

I thank you, sir, for the opportunity you have given me.

[The statement follows:]

STATEMENT OF CHARLES FELTON, M.D.

Mr. Chairman, members of the Subcommittee, I am Dr. Charles Felton, Clinical Professor of Medicine at the College of Physicians and Surgeons, Columbia University. I am appearing today on behalf of the North American Region of the International Union Against Tuberculosis and Lung Disease. The IUAT-LD was established in 1920 and has approximately 120 member countries including the United States, represented by the American Lung Association and its medical section, the American Thoracic Society.

I welcome this opportunity to support increased funding for the tuberculosis control efforts of the United States Public Health Service. At the outset, Mr. Chairman, I would like to thank you for the Subcommittee's continued support for the Project Grants for Preventive Health Projects for Tuberculosis. This program was reauthorized in the last Congress and an important new component was added to that authority, provision for research activity. Recently the House Subcommittee on Health and Environment reported a bill which would provide further reauthorization of the program. The Subcommittee spent considerable time addressing the critical program concerns raised in the Strategic Plan for the Elimination of Tuberculosis and the role of the project grant in this Plan. The IUAT-LD recommends that the full authorized level of $36 million be appropriated for the Tuberculosis Project Grants and that monies be allocated through the set-aside for new research initiatives within the Centers for Disease Control and the National Institute for Allergy and Infectious Diseases.

TUBERCULOSIS MORBIDITY

It is estimated that worldwide, each year, 8 million new cases of tuberculosis occur and that 3 million people die because of this disease. It is estimated that tuberculosis is responsible for approximately one-quarter of the preventable deaths in the world. It is one of the most prevalent infections in the world--it is estimated that over one-half of the world's population is infected with the tubercle bacillus. The worldwide tuberculosis problem has a significant impact on the United States since a significant portion of our new cases--22%--occur in foreign-born individuals.

Although tuberculosis is a preventable and curable disease, it persists as a public health problem in the United States. Significant progress has been made since the U.S. Public Health Service was created in 1944, but much remains to be done as evidenced by the fact that 22,436 new cases were reported in 1988 and provisional data for 1989 indicate that the incidence rate of new cases will essentially equal that of 1988.

An estimated 10 million Americans are currently infected with tuberculosis, and the majority of new cases occurs in this group. From 1953 through 1984 a significant decline in the number of new cases of tuberculosis was experienced. However, since 1984 the long-term rate of decline has stopped. Based on data from the Centers for Disease Control, an estimated 15,000 excess cases occurred since the stop of the previous decline.

Today, marked increased in tuberculosis in the United States occurs in specific populations:

- o persons infected with human immunodeficiency virus: HIV infection appears to have increased the incidence of tuberculosis by causing immunosuppression which allows latent TB infection to progress to clinically apparent disease.
- c minorities: nearly two-thirds of the cases now occur among racial and ethnic minorities. The case rate is consistently higher for non-whites, 29 per 100,000 compared to 5.6 per 100,000 in 1985. Over 84% of cases in non-whites can be considered excess cases.
- o children: 1,134 cases were reported in children under 15 years of age in 1988 and 687 cases were reported in children under five years of age. More than 55% of cases in children in 1988 occurred in minority groups.
- o the elderly: among all racial or ethnic groups and both sexes, the tuberculosis case rate is highest in the elderly. The majority of cases occur among the 95% of elderly persons who live in the community, although the case rate is higher among the elderly living in long-term care facilities.
- o the foreign-born: tuberculosis is very common among immigrants, refugees, and migrant workers from high prevalence countries. In 1986, tuberculosis cases among the foreign-born represented 22.6% of all cases reported, and 22.9% of the cases reported in 1988. Nearly 60% of foreign-born cases occur in persons less than 35 years of age at the time of arrival in the United States and are potentially preventable.

THE ELIMINATION PLAN FOR TUBERCULOSIS

In 1987, the Advisory Committee for the Elimination of Tuberculosis was established within the Department of Health and Human Services to provide recommendations for the development of new technology, application of prevention and control methods, and management of state and local programs aimed at the elimination of tuberculosis. The IUAT-LD representative in the U.S., the American Lung Association, endorses the Committee's recommendation that the United States establish the goal of tuberculosis elimination by the year 2010 at a case rate of less than 0.1 per 100,000 population, with an interim target of a case rate of 3.5 per 100,000 by the year 2000. Secretary of Health and Human Services, Dr. Louis Sullivan, has publicly endorsed the recommendations made by the Advisory Committee and has firmly established the goal of tuberculosis elimination as Administration policy. We applaud this commitment by the Executive Branch.

The Project Grants for Tuberculosis for Preventive Health Projects, an existing program administered by the Centers for Disease Control, is critical to many components of the Elimination Plan. The Grant Program provides cooperative agreements for tuberculosis control activities to state and local health departments in high incidence areas. It was developed to intensify programming activity--specifically outreach efforts--in high incidence areas. Expansion of this Grant Program is necessary to provide the additional resources to the CDC and state/local health departments for the elimination of tuberculosis. In addition to current activities, such as directly supervised therapy for noncompliant patients, additional resources would allow implementation of rapid reporting of new cases, and provide new and increased services to target high-risk populations such as the foreign-born.

An expanded tuberculosis control program effort, as recommended by the Committee for the Elimination of Tuberculosis, would not only prevent the majority of tuberculosis cases in the United States but also save health care dollars. It is estimated that without full implementation of the Plan, elimination of tuberculosis will not be achieved until as late as 2072. It is estimated that more than 664,000 cases of tuberculosis will be reported in this period and of these cases, 64% would be preventable. In 1988 dollars, the prevention of more than 426,000 cases represents a savings of approximately $6.1 billion.

The Union, therefore, recommends the Subcommittee appropriate $36 million--the full authorized level--for Tuberculosis Project Grants.

RESEARCH INITIATIVES

It is paradoxical that we can talk about millions of tuberculosis cases and deaths worldwide in one paragraph and eliminating this disease in the next, but to eliminate tuberculosis in the U.S. and worldwide will require far more intensified and widespread use of existing prevention and control methods, the development of new treatments, diagnostic and prevention technologies, and the rapid transmission of newly developed technologies to the field.

A key component of the Plan for the Elimination of Tuberculosis is the development and evaluation of new treatments, and diagnostic and preventive technologies. The current tools in use for addressing the tuberculosis problem are unchanged from those used for the past three decades and they are manifestly inadequate.

In 1982 a Joint Study Group of the World Health Organization and the International Union Against Tuberculosis pointed out the need for additional research in tuberculosis, stating that this need exists in developed as well as developing countries. At a conference in June 1985 sponsored by the Centers for Disease Control, the National Institutes of Health, the American Thoracic Society, and the Pittsfield Antituberculosis Association, specific research recommendations were developed. A working conference was convened in February 1988 as a follow-up to address research initiatives related to the immunology of tuberculosis. An additional working conference is scheduled for December 1990 to address future directions for tuberculosis research.

Support for tuberculosis research initiatives outside of the Centers for Disease Control is concentrated within the National Institute for Allergy and Infectious Diseases. The overall support within this Institute for research specific to M. tuberculosis has increased from $323,000 in FY 79 to $2.7 million in FY 89, funding 4 grants and 1 contract and 19 grants and 1 contract respectively. Part of this significant increase is due to an RFA in FY 88, "Research Leading to an Accelerated Decline in Tuberculosis Mortality and Morbidity". A total of 36 applications were submitted in response to the RFA and 8 were funded in FY 89. Most of the new projects focus on improvement of diagnostic techniques and development of a new vaccine.

It is clear that there are other excellent applications not currently funded. Further, there is growing interest within the NIAID in initiating a program for the development of new drug therapies. The International Union Against Tuberculosis and Lung Disease recommends that $10 million be appropriated through the research set-aside for expanded tuberculosis research activity within the National Institute for Allergy and Infectious Diseases.

In summary, Mr. Chairman, tuberculosis is an infectious disease which can be transmitted without regard to geographic or governmental boundaries. It is a public health problem not only of national but international scope. Its prevention, control, and elimination require a strong federal commitment and the recognition of the role of the United states as a leader in the fight against tuberculosis.

Senator INOUYE. Thank you.

It would appear from your testimony that the incidence throughout the Nation and the world has increased instead of decrease since 1984. Is that correct?

Dr. FELTON. That is correct, sir. There was a progressive decline in the disease at a rate of about 5 percent per year during the latter 1950's, 1960's and 1970's. In 1984 that decline stopped. And in 1985 the rate went up by 2.6 percent and has been steadily around that rate since that time. It is especially because of the societal problems that we are now facing of poverty and so forth, but especially the HIV infection that is the cause of that increase.

Senator INOUYE. Is there any possibility for a vaccine?

Dr. **Felton**. Yes, sir; that is one of the things that I have mentioned in my formal statement there. But the Centers for Disease Control and the NAID is working on a vaccine as well as on new drug treatment programs. And the immunologic aspects is where the hope of conquering this disease really rests.

Senator **Inouye**. I thank you very much, Doctor.

Dr. **Felton**. Thank you, sir.

Senator **Inouye**. We will do our best to help you, sir.

STATEMENT OF LEIGH CALLAHAN, REPRESENTATIVE, ARTHRITIS FOUNDATION

Senator **Inouye**. Our next witness is Ms. Leigh Callahan representing the Arthritis Foundation.

Ms. **Callahan**. Senator Inouye, my name is Leigh Callahan, and I am a volunteer with the Arthritis Foundation. I appear today on behalf of the Arthritis Foundation, which is a national voluntary organization with over 70 chapters throughout the United States.

The Arthritis Foundation represents the 37 million individuals in the United States who have arthritis. They are vitally interested in Arthritis research and the appropriations for the National Institute of Arthritis, Musculoskeletal and Skin Diseases.

The research and training supported by NIAMS had direct and profound impact on people with arthritis. Let me share some demographic and economic facts about arthritis. There are over 100 forms of arthritis. And as I mentioned previously more than 37 million people have arthritis in the United States—that is 1 in 7 people in the United States. Of individuals that are over age 65 years of age, one in two individuals have arthritis.

Senator **Inouye**. You are looking at me when you say that.

Ms. **Callahan**. One in every three families has a member with arthritis, so someone you know well has arthritis. Arthritis strikes people between the ages of 20 and 50. Most often, it is a chronic disease lasting a lifetime. Approximately 250,000 children in the United States have arthritis.

Each year arthritis affects about 1 million more Americans. That is, one every 33 seconds. Some of the economic facts we deal with are that $8.6 billion are spent annually on cost to the economy in lost wages and medical bills. Arthritis is one of the leading causes of industrial absenteeism, and after heart disease, the second leading cause of disability payments. Arthritis accounts for 500 million days of restricted activity and 27 million days of work loss.

The cost of treating arthritis is high. It is an estimated $35 million annually in medical costs. Currently the Federal investment in research on arthritis and related disorders amounts to less than $3 per person, compared to an average of $150,000 per person, it costs for the care and treatment.

The Arthritis Foundation supports research to find a cure for and the prevention of arthritis. They also support research seeking to improve the quality of life for those affected with arthritis. Therefore, we are concerned about the funding of arthritis research within all levels of government and the health care system.

Congress established the National Institutes of Arthritis, Musculoskeletal and Skin Diseases in 1985. NIAMS as demonstrated and discussed by the representative from DEBRA has been consistently underfunded in comparison to sister Institutes. This is demonstrated by the fact that NIAMS consistently has lower award rates and priority scores.

NIAMS covers more different diseases that affect more people than any other institute at the National Institutes of Health. It attracts the highest quality of research applications and yet, it only gets 2.2 percent of the NIH budget.

Today we are asking that Congress add $50 million over the President's budget for NIAMS. This is a modest and reasonable request. This increase will provide for a number of things. It would allow 63 new competing grants bringing the award rate to 28 percent and the pay line to 25 percent. It would add four new centers for skin diseases to complete the plan for six such centers. It would fund 60 additional training positions which are vitally important for an Institute that covers such a large and varied group of diseases.

Finally, it would add $6 million to an intermural program that is woefully inadequate to the mission of the Institute. And most importantly it would bring the work of the Institute more in line with both its responsibilities and its research opportunities.

PREPARED STATEMENT

Mr. Chairman, I want to thank you today for the privilege and opportunity to present testimony on behalf of the Arthritis Foundation. I would like to have my full statement submitted for the record, and I will be pleased to respond to any questions you might have.

Senator INOUYE. May I assure you that your full statement will be made a part of the record.

[The statement follows:]

STATEMENT OF LEIGH CALLAHAN

Mr. Chairman and members of the committee, my name is Leigh Callahan. I am a volunteer with the National Arthritis Foundation. I appear today on behalf of the Arthritis Foundation, a national voluntary health Organization with 70 chapters throughout the United States, that represent the 37 million Americans who have arthritis. They are vitally interested in arthritis research and in the appropriations for the National Institute of Arthritis and Musculoskeletal and Skin Diseases.

Research and training supported by NIAMS has direct and profound effects on people with arthritis. Let me share some demographic and economic facts about arthritis with you. There are over 100 forms of arthritis. As I stated previously over 37 million people have arthritis. One in every seven people in the population as a whole and one in two Americans over 65 have arthritis. One in every three families is affected. Someone you know well has arthritis.

Arthritis often strikes people between the ages of 20 and 50, and in most people it is chronic, lasting for life. Approximately 250,000 children have arthritis. Each year, arthritis affects about one million more Americans—1 every 33 seconds. Women are affected by arthritis twice as often as men, a total of 23 million women of all ages. The largest segment of Americans at risk—the elderly—will double over the next 50 years.

ECONOMIC FACTS

The annual cost to the economy in lost wages and medical bills is $8.6 billion. Arthritis is one of the leading causes of industrial absenteeism and, after heart disease, the second leading cause of disability payments. Arthritis accounts for 500 million days of restricted activity and 27 million days lost from work. The cost of treating arthritis is high—an estimated $35 million annually in medical cost.

Currently, the Federal investment in research on arthritis and related disorders amounts to less than $3 per person, compared to an average $150,000 per person it costs for care and treatment. The Foundation supports research to find a cure for and prevention of arthritis, and seeks to improve the quality of life for those affected with arthritis. Therefore we are concerned about the funding of arthritis research within all levels of government and the health care system.

Congress established the National Institutes of Arthritis and Musculoskeletal and Skin Diseases in 1985. NIAMS has been consistently underfunded in comparison to its sister institutes as demonstrated by the fact that NIAMS consistently has lower award rates and priority scores. NIAMS covers more different diseases that affect more people than any other institute, and it attracts the highest quality of research application, yet it gets only 2.2 percent of the NIH budget.

We ask that Congress add $50 million over the President's budget for NIAMS. This is a modest and reasonable request. This increase would provide for 63 new competing grants bringing the award rate to 28 percent and the payline to 25 percent. It would add 4 new centers for skin diseases to complete the plan for 6 such centers, it would fund 60 additional training positions, vitally important for an institute that covers such a large and varied group of diseases. Finally, it would add six million dollars to an intramural program that is woefully inadequate to the mission of the institute. Most importantly, it would bring the work of the institute more in line with both its responsibilities and its research opportunities.

Mr. Chairman and members of the committee, thank you for the privilege and opportunity to present testimony on behalf of the Arthritis Foundation. I will be pleased to respond to any questions the committee may have.

Senator INOUYE. I must have one of the 100 different types of arthritis you have mentioned and having reached that glorious demarkation of 65, I am one of the one out of two I suppose. But I will discuss this matter with my colleagues, and I will do my best to convince them that this matter should be increased.

I would assume that with the growth of the aged segment of our population that means there are more arthritis cases in this Nation.

Ms. CALLAHAN. Oh, yes; the prevalence will just be increasing as the age increases.

Senator INOUYE. I will do my best.

Ms. CALLAHAN. Thank you very much.

PREPARED STATEMENT OF DR. GORSKI

Senator INOUYE. Thank you. And without objection the statement submitted on behalf of the Endocrine Society by Dr. Gorski of the University of Wisconsin will be made part of the record.

[The statement follows:]

STATEMENT OF JACK GORSKI, PH.D., PRESIDENT-ELECT, THE ENDOCRINE SOCIETY

Chairman Harkin, and members of the subcommittee, my name is Jack Gorski, Ph.D., President Elect, Endocrine Society, it is truly my distinct honor to appear before you today to discuss the welfare of the National Institutes of Health and represent the Endocrine Society, which is made up of over 6,000 endocrinologists, physicians and investigators, across the Nation. I am a professor of biochemistry at the University of Wisconsin where I teach as well as direct a research program on the mechanism of action of estrogenic hormones. I would like to present a few brief comments, and request that you would include my complete statement in the record.

This year I come before you to lend my support for increasing the NIH budget in order to increase the number of research project grants which are supported by the National Institutes of Health. Over the past 100 years, the NIH has been privileged. Congress took the charge in assuring that Americans would be at the forefront of medical advancement—that we would set the pace for the rest of the world to follow. Surely, the work of this distinguished subcommittee has served to foster this noble cause and as a teacher and researcher, I commend you in your efforts. However, in the same breath, I must issue a pessimistic viewpoint. As I am sure you are aware, our past Federal research investment is being threatened. We have failed to keep up with inflation, and now, after a decade of insufficient funding, we find ourselves unable to fund even half of the meritorious research.

The RO1 pool, investigator initiated research, is the cornerstone of the medical research advancement in this country, without it, our scientific advancement will be crippled. However, both the NICHD and the NIDDK will only be able to fund approximately 21 percent of the approved research grants. This means that almost 80 percent of the meritorious research will lay by the wayside unless the additional funds are made available.

Our inability to adequately support research is a direct result of research opportunities out pacing funding. This will ultimately be disastrous for our research enterprise. Year after year we subject our research project grants to devastating "downward negotiations" which essentially serve as budget cuts. Under the fiscal year 1991 Administration Budget, the NIH estimates that downward negotiations will be in the range of 14 to 20 percent. The two basic Institutes which conduct endocrine research (although almost all of the Institutes including NCI conduct some form of endocrine research) are the National Institute on Child Health and Human Development and the National Institute of Diabetes, and Digestive and Kidney Disorders. It is estimated that they will have downward negotiations of approximately 14 percent and 11 percent respectively, for research grants. Centers in these two instances would suffer 21.6 percent and 30 percent downward negotiations respectively.

If we continue to stretch the Federal research dollar we must also recognize that at some point, it will no longer be feasible to continue to support our research program.

As I am sure you are aware, scientific advancement often happens when we least expect it. If we continue to fund such a small percentage of our worthy research, we may never come to realize our expectations and certainly, opportunities are lost each time we turn an investigator away. The opportunity for a successful research career for many talented young investigators has become virtually impossible.

Because of the line work of this subcommittee the research community was fortunate to restore the number of training grants that the NIH was able to fund. However, if we are failing to fund the grants submitted by these young scientists mentors, and as they watch as well-respected members of the research community fail to obtain funding from the NIH, it is unlikely that we will be able to entice young investigators into the field.

This year, the Ad Hoc Group for Medical Research is recommending that the NIH receive a budget of $9.2 billion. This is approximately $1.4. billion over the President's fiscal year 1991 request. This would allow for a 30 to 33 percent award rate—fully funded. The Endocrine supports this figure as a worthy starting point. We need to bring our Federal research program back to its premier status experienced over a decade ago.

We are witnessing a time when an increasing number of countries are investing more into medical research than the United States. We must be committed in our investment in the future. The health of our Nation and the world depends upon the foresight of the Congress and the support of the American people. As an endocrinologist, I have had the opportunity to see science advance in a great many ways.

This year both the House and the Senate have introduced legislation which would institute contraceptive and fertility research centers across the Nation. The NICHD would be primarily responsible for the conduct of these centers, and yet, without funding, these centers would only serve to take away funds from individual investigators and increase the hardship which is being experienced by the NICHD. The Endocrine Society is calling upon this subcommittee to assure that ample money be placed in the programs which will ultimately yield a significant benefit for our Nation.

Another area of research with which the Endocrine Members are involved is that of diabetes research. It is estimated that diabetes costs this nation $20.4 billion direct and indirect costs annually. In fiscal year 1990 it is estimated that NIH will invest $252 million in diabetes research, NIDDK will fund approximately $150 million of that total, just a small fraction of what this disease costs us annually.

Through our Federal research investment the advancements have been made. One example of this is our understanding of the gene structure of the number of hormones and their receptors. This will lead to future treatments using human hormones produced by recombinant DNA technology. The use of erythropoietin is an example of such a development.

An issue which is of great concern to the Endocrine Society is that regarding the use of animals for research. Only through animal research are we able to find models for which to test potential life saving treatments. The benefits which have been provided to this Society as a result of animal research is experienced daily. It is essential that sufficient funds be provided to the intramural and extramural programs in order to assure the highest quality care must be given to these animals if we are to act in a civilized and human manner as well as for the purposes of conducting top notch research. We appreciate and need your continued support in this area. Your support of the legislation introduced by Senator Heflin is an example of the positive steps Congress is willing to take to assure that animal research continue at a high level.

Research is an investment in our future. For every $1 spent on medical research, $13 is saved in lost wages, health care costs and productivity. Currently, we spend $2,000/per person on health care expenditures, and only $35/per person on medical research. If we make the initial investment in research a priority, we will not only find savings in the end, we will have provided for a more productive, healthier society—a product which cannot be properly appraised.

I would like to thank the Subcommittee for their patience and consideration of my remarks. The future of our Federal research programs rests with the wisdom of the Congress. Your efforts on behalf of the NIH are greatly appreciated by the members of the Endocrine Society. If we can provide any information regarding specific endocrine research related issues or funding needs we would be more than happy to provide that information to you. This concludes my remarks, and would be happy to answer any questions you may have.

Senator INOUYE. I gather Dr. Gorski had to leave, because he had other appointments.

STATEMENT OF SOPHIE SHIOSHILOS, REPRESENTATIVE, COOLEY'S ANEMIA FOUNDATION

ACCOMPANIED BY PETER CHEICO, MEMBER, BOARD OF DIRECTORS

Senator INOUYE. May I now call on Ms. Sophie Shioshilos representing the Cooley's Anemia Foundation.

Ms. SHIOSHILOS. Senator Inouye, I am Sophie Shioshilos, and I am here to represent the Cooley's Anemia Foundation. With me is Peter Cheico a member of the foundation's board of directors. I am a patient by the way.

First I want you to know that all of us at the Cooley's Anemia Foundation recognize that you have been a leader on this committee for our concerns. And the bill report language that you have provided over the years have contributed enormously to the health of our patients and to the research we so badly need. I will read our recommendations in short form and ask that my statement be made a part of the record.

The Cooley's Anemia Foundation, Inc. has the following recommendations for appropriations for research and patient care in regard to Cooley's anemia.

First, oral chelator. The National Institute of Diabetes, Digestive, and Kidney Diseases has been the lead Institute dealing with animal studies on the removal of iron caused by excessive blood transfusions. The compounds—the NIDDK has tested nearly 300 compounds over the past 15 years, and 4 new compounds have been shown to be possibly effective in animals.

We believe $1 million should be added in fiscal year 1991 to this Institute, specifically earmarked for the purpose of continuing these animal tests. Currently patients require infusion of a chelation drug by needle and pump for over 8 hours a day.

Second, oral chelator. We request that the Congress give the National Heart, Lung, and Blood Institute support for the development of human clinical trials just as soon as the animal trials are completed. We recognize that time is not yet present. Nevertheless, we believe appropriate bill report language should stress the opportunities available and urge the NHLBI to begin to complete its action plan for moving from the animal trials to human trials.

Three, intramural research program. The NHLBI plans to lead an inter-NIH effort to establish a clinical bone marrow transplant unit. The Cooley's Anemia Foundation strongly supports the availability of a dedicated facility for bone marrow transplant research which would enable intermural scientists at the NIH to extend findings from their basic research laboratory and attempt innovative, experimental and therapeutic interventions for specific diseases such as Cooley's anemia.

Four, long-range plan. We support the request made by the American Society of Hematology for the development at the NIH of a long-range plan for gene therapy research which would utilize the expertise, not only of researchers and administrators at the NIH, but also research hematologists across the country and the leadership of voluntary health groups such as Cooley's Anemia Foundation.

Five, maternal and child health. We recommend that the maternal and child health program of the Health Resources Administration be permitted to continue the 15 percent set-aside for the programs of regional and national significance under which centers of Cooley's anemia patients now operate. And that funding for these centers be continued. These centers have proved excellent research resources.

PREPARED STATEMENT

Six, in regard to funding levels for the National Institutes of Health and the institutes which support research on Cooley's anemia we recommend NHLBI $1.48 billion, NCI $2.4 billion, NIDDK $697 million, NIH overall $9.2 billion.

Thank you.

[The statement follows:]

STATEMENT OF SOPHIE SHIOSHILOS

Mr. Chairman, this is the thirteenth year that representatives of the Cooley's Anemia Foundation have appeared before you.

I am Sophie Shioshilos, Secretary of the Thalassemia Action Group (TAG). With me is Peter Cheico, a member of the Cooley's Anemia Foundation Board of Directors and Executive Committee.

As you have heard in the past, Cooley's Anemia (also known as Thalassemia) is a fatal blood disease that is passed from parent to child, frequently striking children in America of Mediterranean-American ancestry, including those of Italian and Greek descent, as well as Syrian, Israeli, and other population groups. Recently there has been an increase in the number of individuals manifesting this disease in America because of the great increase in the number of immigrants from Asia.

We have a number of recommendations to make to you, Mr. Chairman, which are contained both in the fact sheet covering our testimony and also at the end of this testimony.

RESEARCH ADVANCES

We know that you are deeply concerned to learn about recent advances that have occurred as a result of research at the National Institutes of Health.

In the field of Cooley's Anemia, we have a good deal to report.

The National Heart, Lung and Blood Institute (NHLBI) last year funded several studies of an oral chelator, which we will describe below, and is preparing a program of human clinical trial research if animal studies are successful (see below). Additionally, this institute has taken a very serious interest in research regarding Cooley's Anemia as it relates to the potential cure of the disease through gene therapy and bone marrow transplantation. We will be discussing these opportunities later in the testimony.

The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) has been a strong supporter of Cooley's Anemia oral chelation research. This institute has been searching for drugs to remove iron since 1974. We have had an effective infusion chelator since 1975, and this institute has supported testing of nearly 300 compounds over the past 10 years to find an oral chelator. The institute now believes that four compounds may well be shown to be effective in animals when given orally. The Foundation is very encouraged by this information and encourages the Congress to fund these research programs more fully. It is our understanding that it will require about $1 million next year for the continuation of the animal testing, and that the animal testing will require another two years to complete. It should be noted that if one or more of these drugs is shown to be acceptable in animal studies, it will then take another three-five years of human trials (funded by NHLBI) before these drugs would be widely available for use in patients. However, from our point of view, the identification of these drugs represent important breakthroughs and we request that the NIDDK receive specifically earmarked funds to pursue these studies now.

In summary, then, in respect to research advances during the last year, please understand we are enormously enthusiastic about the progress that has been made and the avenues that are open to us, not only in terms of the oral chelator, but also in terms of the opportunities presenting themselves in the area of gene therapy and bone marrow transplantation.

RECOMMENDATIONS:

- National Heart, Lung and Blood Institute (NHLBI)

Support for Oral Chelator: We request that the Congress give the NHLBI support for the development of human clinical trials just as soon as the animal trials are completed. We recognize that time is not yet present; nevertheless, we believe appropriate bill report language should stress the opportunities available and urge the NHLBI to begin to complete its action plan for moving from the animal trials to human trials.

Intramural Research Program: The NHLBI plans to lead an inter-NIH effort to establish a Clinical Bone Marrow Transplant Unit. The Cooley's Anemia Foundation strongly supports the availability of a dedicated facility for bone marrow transplant research which would enable intramural scientists at the NIH to extend findings from their basic research laboratory and attempt innovative, experimental, and therapeutic interventions for specific diseases such as Cooley's Anemia.

National Bone Marrow Donor Program: It will be recalled by this committee that the National Marrow Donor Program was transferred from the Department of the Navy to the NHLBI in 1989. The Foundation last year supported the addition of funds to the NHLBI for the development of this program, and we are pleased that the committee agreed to do that last year. As has been testified to by the Director of the NHLBI earlier, the program serves as a focal point for bone marrow research and includes the National Bone Marrow Registry, which is a computerized file of persons who have been HLA-tissue typed and have agreed to participate as donors. We support increased funding for this project. We cannot say enough about the fine, strong support given to our own voluntary efforts by Dr. Claude Lenfant, Director of the NHLBI, and Dr. John Hoak, Director of the Division of Blood Diseases and Resources at the NHLBI. They have given extraordinary guidance to the Foundation and have kept us continually informed of research advances and opportunities.

. National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK)

Oral Chelators: The NIDDK has been the lead institute dealing with animal studies on the removal of iron caused by excessive blood transfusions. Cooley's Anemia patients must receive frequent blood transfusions, thereby building up a large amount of accumulated iron in the heart and other organs. This excess iron eventually is toxic to the liver and heart and eventually causes death. The first drugs for the removal of this iron that were discovered required continuous injection by needle and pump, for eight to ten hours every day. While effective in prolonging the lives of patients, there is a problem with compliance with the continuous use of this injection procedure among Cooley's Anemia patients because it is a very difficult regimen to follow. Therefore, there have been needless deaths, largely because of noncompliance. This problem has led to the NIDDK's continuing to conduct extensive searches for other compounds that might be taken orally which would, of course, increase compliance enormously. As indicated above, that institute has tested nearly 300 compounds over the past 10 years and four new compounds have been shown to be possibly effective in animals. We believe $1 million should be added to this institute in 1991, specifically earmarked as indicated above, for the purpose of continuing these animal tests.

Gene Replacement Therapy: Gene replacement therapy is another area of work that the NIDDK has been active in. This institute has been concerned with much of the basic research supporting Cooley's Anemia care advances.

For many years, the NIDDK has been supporting research on the structure and regulation of genes, and the relationship between gene defects and diseases. Because of their work, scientists now know the precise nature of the genetic defect in some inherited diseases, including Cooley's Anemia. They also know how some of the genes are regulated. Additionally, the necessary techniques for replacing defective genes with normal ones are well along in development and include generating copies of the normal gene, inserting it in the cells and transplanting the cells into recipients, possibly by bone marrow transplantation. The first experiments in humans are still in a very preliminary stage but the promise of gene therapy is that it can provide a cure for diseases like Cooley's Anemia.

We urge a major initiative in this institute to accelerate research in gene replacement therapy.

Long-Range Plan: We support the request made by the American Society of Hematology for the development at the NIH of a long-range plan for gene therapy research which would utilize the expertise not only of researchers and administrators at the NIH, but also research hematologists across the country, and the leadership of voluntary health groups, such as the Cooley's Anemia Foundation.

The NIDDK leadership in hematology, including Dr. Gary Striker and Dr. David Badman, have been constant in their attention to our concerns. We owe them an enormous debt of gratitude; their close attention to research needs in Cooley's Anemia has helped us to sustain the interest of our volunteers over the years.

Mr. Chairman, we know that agency leaders such as those from NHLBI and NIDDK are not praised often enough by those who benefit from their work -- we want you to know that they deserve our strongest praise.

Maternal and Child Health: We recommend that the Maternal and Child Health Program of the Health Resources Administration be permitted to continue the 15% set-aside for the programs of regional and national significance, under which centers for Cooley's Anemia patients now operate, and that funding for these centers be continued. These centers have proved excellent research resources. Mr. Chairman, thank you for giving us this opportunity to appear before you and we will be pleased to answer any questions you may have.

April 3, 1990

The Honorable Daniel K. Inouye
SH 722 Senate Hart Building
Washington, DC 20510

Dear Senator Inouye:

We are pleased to enclose the following statement for inclusion in the Record at the point where the Cooley's Anemia witnesses appeared before you (#18) on Wednesday, March 28, 1990:

The Cooley's Anemia Foundation estimates that there are 1,000 patients in the United States and approximately 300,000 patients worldwide. The estimated number of trait carriers in the United States is two million and 200 million worldwide. These figures have been documented by the World Health Organization which has described Cooley's Anemia, known internationally as Thalassemia, as the world's most common childhood blood dyscratia.

Sophie Shioshilos, our witness, indicated to you that the Cooley's Anemia Foundation sponsored the Fourth Thalassemia Patient and Parent World Conference which was held March 10 - March 16, 1990. The Cooley's Anemia Foundation also sponsored the Sixth New York Academy of Sciences Cooley's Anemia Symposium, on March 13, 14 and 15. Over 300 patients and parents and 31 international associations attended both conferences.

Associations represented included:

Algeria
Argentina
Australia
Bangladesh
Belgium
Brazil
Canada
Cypress
France
Greece
Hong Kong
India
Indonesia
Iran
Israel
Italy
Liberia
Pakistan
Panama
Portugal
Russia
Saudi Arabia
South Africa
Spain
Thailand
Trinidad
Turkey

The conference programs and press kits are attached for inclusion in the Record. Under the leadership of Robert A. Ficarra, the Cooley's Anemia Foundation was a founder and staunch proponent of the Thalassemia International Federation. The Federal has made major strides in just a few short years and is presently being considered by the World Health Organization as an affiliate organization.

We are also enclosing literature on Cooley's Anemia and the abstract of the Report on the International Workshop on Oral Iron Chelators hosted by the Cooley's Anemia Foundation and the NIH, held on February 21, 1989. The Report highlights the critical need for support of an oral chelator to improve compliance with present Chelation therapy, which is painful, costly, and time consuming. Chelation research is now at the point of a major breakthrough as noted in the workshop abstract.

The Cooley's Anemia Foundation maintains that a major educational program must be undertaken to advise high risk groups and potential carriers, and to create public awareness of the need to alleviate the void in patient services throughout the United States. These are, however, four clinics in New York State that service Thalassemia patients, which provides screening and genetic counseling. The clinics were established by the Department of Maternal and Child Health under the Sprains program.

On behalf of the patients of Cooley's Anemia, may I take this opportunity to thank you for your continued interest and support in assisting us in advancing the treatment and cure for this fatal blood disease. We are deeply grateful.

Sincerely,

T. G. Piropato
Teresa G. Piropato
National Executive Director

Senator INOUYE. Thank you very much. Approximately how many people in the United States are afflicted with Cooley's anemia? Do you have any idea?

Ms. SHIOSHILOS. We have a patient directory list which we have put together. I believe it is 1,000. Mr. John Grupenhoff is here who is our representative here in Washington. I do not know if he has any idea.

Senator INOUYE. Do you have any numbers that we can put in the record?

Dr. GRUPENHOFF. There have been approximately 3,000 identified. But the number of the trait carriers of the disease is considerably larger, and we would be pleased to put that in the record.

Senator INOUYE. I appreciate that very much.

Is it true that this anemia affects primarily those whose ancestors came from the Mediterranean area?

Ms. SHIOSHILOS. It originates in the Mediterranean area. We recently had a conference in New York City and something like 30 different countries have been represented where the disease and the trait have shown up. For example, India, Pakistan, France, Italy, which are the most obvious, Australia, Canada.

There is through migration that the trait has traveled on to other countries, including Third World countries, Turkey, Russia—we had representatives from all these countries.

Senator INOUYE. And this is passed on from parent to child?

Ms. SHIOSHILOS. It is genetic, right.

Senator INOUYE. So, it is not infectious?

Ms. SHIOSHILOS. No.

Mr. CHEICO. There is no screening currently. I recently became involved as a volunteer. And 8 months ago my daughter was diagnosed with Cooley's anemia. And it is one of the main reasons that I was here today to learn more about it to see what is being done. And we had no idea as parents that we had a risk. And we are told now that 25 percent of every child we had, had the opportunity of having this, the worst form of this anemia.

We have two children. One is perfectly normal. She currently goes through a bimonthly blood transfusion, and next week we are going to be starting with daily infusion pump, which is administering a chelating agent that will grab the iron out of her blood stream and thereby prolonging her life. And we are hoping as parents and with the foundation that the funds being raised will come up with an oral alternative to this nightly treatment. And we are looking forward to a cure.

Senator INOUYE. And you are saying that at the present time there are ways of determining whether you have this gene?

Ms. SHIOSHILOS. It is a simple blood test that can be performed to let you know if you are a trait carrier or not. But unless you have someone in your family who probably has the disease itself. Because the trait has no symptoms. So if you have someone in your family who has the disease itself, you would not know enough to go and ask for this particular blood test. It is not included in a routine blood examination. It is a special test that has to be requested.

Mr. CHEICO. And I have the trait. And I am perfectly normal in every other way. And my wife had the trait, and thereby we had the chance.

Ms. SHIOSHILOS. That is why it is so difficult to grab these people.

Senator INOUYE. Well, I think that there should be an educational program.

Ms. SHIOSHILOS. Definitely.

Senator INOUYE. Well, I thank you very much both of you, it has been most helpful.

Ms. SHIOSHILOS. Thank you.

STATEMENT OF LOWELL A. GOLDSMITH, M.D., REPRESENTATIVE, AMERICAN ACADEMY OF DERMATOLOGY

Senator INOUYE. Now representing the American Academy of Dermatology, Dr. Lowell A. Goldsmith.

Dr. GOLDSMITH. Thank you, Mr. Chairman. It is a pleasure being here.

I am the chairman of dermatology at the University of Rochester in Rochester, NY. And during our long, cold, snowy winter, I often think of your beautiful State. I represent 8,000 dermatologists in the Academy of Dermatology and 2,000 investigative dermatologists in the Society for Investigative Dermatology.

And we are part of a coalition of groups to look for an additional increase in the funding for the National Institute of Arthritis, Musculoskeletal and Skin Diseases—$50 million to bring up its base line to the level intended by Congress.

You have heard a couple of other speakers approach this point. And in my spoken record, I would like to emphasize some points not in my written statement which I hope will be accepted.

In addition to increasing our research grants, increasing our funding to researchers, beginning clinical trials funded by the Institute, which is an extremely important point, we would like those additional funds to follow through on the mandate of Congress to fund four additional research centers and to also enhance intramural research programs of the Institute.

I would like to concentrate on really three groups of people: the patients, Congress, and the researchers. The patients: I think you have heard from patients who have spoken this morning that we are talking about extremely common diseases, the forms of arthritis are very common and similarly forms of eczema and psoriasis are extremely common, lead to loss of work, loss of self-esteem and often to continuous medical care.

You have heard about devastating skin diseases such as epidermolysis bullosa, and there are many other similar skin diseases. These are diseases in which there is really inadequate understanding of the basic path of physiology of the disease and hence there is inadequate treatment. From the laboratory from many of the advances of both cell biology and molecular biology, we know that we have many findings which are being applied to patients but also need additional funding, so that we can continue our applying this to the patient.

Patients are counting on Congress to give us the fuel, which is the money we need to develop and drive the research machine and to take advantage of these advantages.

We are very grateful that Congress and this committee have really understood the need for these diseases. And when this new Institute of Arthritis, Musculoskeletal and Skin Disease was set up in 1985, it was really for the purpose of giving emphasis, visibility and focus on these diseases. It was not set up to give us the worst pay line in the entire National Institutes of Health.

It is ironic, and if that situation had just gone on for 1 year, I guess we could have lived with it. But many of us in the research community understand the financial pressure that Congress is under. But we think to fulfill on your own wishes for this Institute that looking for $50 million would be, you know, effort well spent.

There has been very little real growth in this Institute. In constant dollars the budget of this Institute has gone up 2 percent over a period of 5 years—not 2 percent a year, 2 percent total over 5 years. Congress specifically mandated skin research centers, yet there has only been funding for two of them.

There is another element that has not been spoken about, which is I think extremely important for you and for the entire committee to know and that is researchers as people. I sit on a committee similar to this at NIH where we review research grants. And in fact October I am going to be chair of that committee. We see very, very worthy projects coming in, and we are only going to be able to fund 17 percent of them. Who does not get funded? What happens?

People who do not get funded are people who have been very productive, who have lots of wisdom, broad expertise. And instead of getting a 144 score, they will get a 145 score. Is there a difference between 144 and 145? Of course, there is not.

Who else does not get funded? Junior people we think are people at tremendous risk. These are people who have gone through extensive research, training. And they too may end up just on the line and are told, try next year. We are very afraid that junior researchers are losing faith in the system and will not see that it is a potential career to really go in part of this research system.

Personally, I have faith in the system, I have faith in the process. I have faith in this committee, that this committee can see the need for equity and parody and fairness in this Institute. And that this committee has the desire to fulfill its own mandate for this Institute.

PREPARED STATEMENT

I think there are the people like the various patient advocacy groups we have heard from, from the foundations we have heard from—the other people counting upon us. They have debilitating, life threatening, spirit wrecking diseases. And we all count on you and, I would be happy to answer any questions.

[The statement follows:]

STATEMENT OF LOWELL A. GOLDSMITH, M.D.

Mr. Chairman:

I am Lowell A. Goldsmith, M.D., Professor and Chairman of Dermatology, at the University of Rochester School of Medicine and Dentistry and Chairman of the Council on Research of the American Academy of Dermatology. I am presenting this testimony today on behalf of the more than 8,000 members of the American Academy of Dermatology. I also speak on behalf of the Society of Investigative Dermatology whose membership includes the majority of those doing laboratory and clinical research on the skin and its diseases.

We are grateful for the courtesy this committee has shown to Dr. Peyton Weary, Chairman of Dermatology at the University of Virginia, who has testified on our behalf in previous years. Dr. Weary is the president-elect of the American Board of Medical Specialties and is attending their annual meeting at this time.

We appreciate also the expressions of concern by this committee regarding the low pay line of this institute. The addition last year of $9 million helped us to continue many important research efforts, but, as will be indicated below, the problem has not been completely solved.

Skin Research Successes

I would like to cite some recent examples of successes achieved by skin disease researchers. Within the past year there has been considerable progress and saving of many lives through the use of cultured epidermal cells for patients with severe burns. Culturing skin cells was a laboratory curiosity when I began my own research career, and the techniques have been moved rapidly from the laboratory to direct patient application. These grafts, in addition to saving lives, are able to decrease the scarring, pain and the complications associated with large burns and skin ulcers. Other components of the skin, including melanocytes, the pigment cells, can now be cultured giving hope to those with the disease vitiligo. In Vitiligo there is an absence of pigment in the skin causing extreme susceptibility to sunburn, an increase in skin cancer and marked social limitation sometimes progressive to ostracism.

In another area, the use of vitamin A derivatives in patients with severe acne, psoriasis and the rash associated with AIDS has helped restore these people to full, active and productive lives. Understanding how the drugs work and how they may be made more effective and safer is a major aim of many researchers. During the past year three different receptors for vitamin A derivatives have been found in human skin. When these receptors bind, the drugs become potent switches controlling the cells of the skin.

Research on epidermolysis bullosa continues to help us define the defects in the many types of this life-threatening genetic disorder. The Epidermolysis Bullosa registry, which you funded, is being used by over ten different groups of investigators studying the molecular mechanisms of the disease and should help us develop more effective therapy in future years.

Funding Problems

I could go on discussing the excitement and the opportunities in skin research which will lead to better understanding and better treatment of patients with severe lifelong skin diseases, but in view of the limited time I must focus yourattention on a very serious grey cloud hanging over skinresearch and all other research supported by the NIAMS. I have first-hand experience with the serious restrictions in funding which the NIAMS is facing. I am a member and, in October, will become chairman of the NIH study section which reviews most skin-related research proposals. We reviewed 77 excellent research proposals last month in Bethesda and will be able to fund, at most, 13 of them. That is less than 17% of the grants we felt should be funded. Superior grants which will just miss funding were submitted by senior investigators who have contributed important research for over twenty years and have the abilities, perspective and wisdom we need for the future. Perhaps a more serious problem is the grants from young investigators which will not be funded. These investigators have devoted years to research training and when they apply for their own awards, we must say "you just missed, try again". Academic manpower is our most precious resource and the funding situation at the NIAMS is giving those beginning research careers a very negative message. Our nation cannot afford to lose this resource.

Pay Lines at NIAMS

You have heard about pay lines and award rates in the past; NIAMS for several years has had one of the lowest award rates of any of the NIH institutes. You also have heard that this institute was initially under funded when the National Institute of Arthritis and Metabolic and Digestive Diseases split into the NIAMS and the NIDDK. These problems must be corrected as soon as possible. A coalition of the professional and patient advocate groups associated with the mission of NIAMS has been developed and our goal is to have you add $50 million this year to the NIAMS FY 1990 base budget so that this institute can fund research at the same pay lines and award rates as other NIH institutes, and accomplish other goals, described below.

Skin Disease Research Centers

The dermatologic research community is grateful for the funding of the two skin disease centers which have already begun active programs, including studies of the cell and molecular biology of the epidermis and the skin's response to external chemical agents and sunlight. The Congress several years ago in appropriations bill report language called for six such centers; additional funding is needed to establish them; the $50 million add-on will permit their funding.

Current Research Needs

Next month NIAMS will help sponsor a conference on gene mapping in skin disease. Gene mapping studies during the past year allowed definition of the primary defect in cystic fibrosis and using similar strategies would make it possible to determine the primary defect in diseases such as psoriasis and eczema.

Alopecia, or hair loss, although not life threatening, is one of those processes which can make patients miserable and emotionally unable to function. This fall NIAMS will sponsor a conference on growth control in alopecia which should lead to outstanding research in this important field.

In order to achieve progress in this area we must be able to fund the needed work.

Also, the intramural skin biology program within NIAMS is off to a good start but it requires increased funding to take advantage of the advances in cell and molecular biology which can now be applied directly to the understanding of human disease. The budget we have requested will permit us to reach this and previously described goals.

Other Agencies

We have interests in several other institutes beside the NIAMS. We support the increases in funding requested for the National Cancer Institute. The NCI Dermatology Intramural program is a major national resource for both research and training. Melanoma and non-melanoma skin cancer are still increasing in frequency.

The importance of sunlight as a causal factor in skin cancer was underscored last year at a successful NIH-sponsored Consensus Conference on the effects of ultraviolet light on the skin. (NIAMS was the sponsor; the NCI Dermatology Intramural program participated in a major way, as did dermatologist researchers from all over the country. This illustrates the closeness and collegiality of the entire community in research effort's.)

The National Institute of Environmental Health Science needs increased funding so that the studies it supports on the environmental effect of agents, including ozone, can be furthered. Occupationally-related skin diseases remain a major cause of temporary and permanent disability in our country and for this reason increased support for NIOSH as well as for NIAMS and NIEHS must be a major priority.

Research supported by the National Institute of Allergy and Infectious Disease on AIDS and the Kaposi's sarcoma associated with it (manifested on the skin) is very important and we support increased funding for NIAID. Skin diseases of the aged are increasing with the aging of our population. A major conference on skin changes associated with aging was co-sponsored by NIAMS and the National Institute on Aging last spring and we expect a request for proposals for research in this important subject. Funds should be made available to fund those proposals which merit funding.

Recommendations

We support the recommendations of the Coalition for the National Institute of Arthritis and Musculoskeletal and Skin Diseases in the request for $50 million to be added to the FY 1991 NIAMS budget beyond the FY 1990 level. This will permit the NIAMS overall to:

- achieve parity with other NIH institutes as to pay lines;
- increase funding from 16.6% to 28% of approved grants;
- train 60 additional researchers;
- support urgently needed clinical trails;
- fund four additional centers; and
- increase the intramural research program to $19,922,000, a $7 million increase.

For skin disease research, specifically, such an add-on would permit;

- the full funding of skin disease research grants;
- the funding of the four skin disease research

centers called for by the appropriations committee earlier; and

- the opportunity to fund research advances described above.

In summary, we have reached the golden age of biomedical research with the advances in molecular and cellular biology beginning to pay off on their promises to improve the health of the American people.

There is need for a $50 million adjustment to allow the NIAMS to participate in this effort. I trust the members of the committee will consider my request during your deliberations. I thank you for your continued interest and support of our efforts and for the opportunity to appear before you.

I will be pleased to answer any questions you may have.

Senator INOUYE. How are we doing in the ailments of psoriasis and eczema?

Dr. GOLDSMITH. I think we are learning much, much more about psoriasis. That there is a drug that has been used to—that there is a new drug that we have been using in psoriasis. It is a drug called cyclosporin. It is a drug that has been used in various organ transplantation. And it works very well in psoriasis. It has some toxic effects, but it is extremely important, because it has focused us on the potential for the immune system having a major role in psoriasis.

Psoriasis often has a very bad arthritis associated with it. And that would fit in with an immune ideology. And we think it is important that skin and arthritis and muscular skeletal diseases are all parts of this Institute. Because all these diseases probably run together when we finally understand what is going on at very basic levels.

So that thinking about immune mechanisms in psoriasis have made us think about therapy a very different way. Many people with psoriasis have their attacks of psoriasis precipitated by strep, sore throats, again suggesting that there is some kind of an immunological mechanism.

To really follow through on these clinical findings, people like me have to go back to my lab and really work on the detailed mechanism, so that safe and effective therapies can result.

Senator **Inouye**. One of my colleagues came down with what is commonly called shingles. Is that a skin ailment?

Dr. **Goldsmith**. It certainly is. I see patients with shingles at my practice. What shingles is, it is really the same virus that cause chicken pox, the varicella virus. That virus is sort of stored in the body for years and years. And then at some point—sometimes associated with other diseases or sometimes with no other disease—will just come out.

That virus is stored in portions of the nervous system. And people are now able to work with some of the newer genetic techniques to find just those little remnants of that virus exactly where they are stored.

This is essentially a golden age of biology and genetics. We have multiple new ways of working with diseases. We can look for genes and find them sometimes within weeks. And those of us in the research community get very frustrated, when for the lack of funding, we cannot proceed.

We realize that we have a debt in this country. We realize that we have a budget in deficit. But when we see those opportunities and we see that excitement, you know, not to be able to cross that threshold is what makes us give up our time in the lab to come down to try to tell you of the excitement and potentials we see in research.

Senator **Inouye**. We will do our best to alleviate part of the frustration.

Dr. **Goldsmith**. Thank you, sir.

Senator **Inouye**. Thank you.

STATEMENT OF JEROME C. GOLDSTEIN, EXECUTIVE VICE PRESIDENT, AMERICAN ACADEMY OF OTOLARYNGOLOGY, HEAD AND NECK SURGERY

Senator **Inouye**. Our next witness is Dr. Jerome C. Goldstein, the American Academy of Otolaryngology, Head and Neck Surgery.

Dr. **Goldstein**. I am Dr. Jerry Goldstein, executive vice president of the American Academy of Otolaryngology, Head and Neck Surgery—the largest organization of the otolaryngologists, head and neck surgeons in the world with more than 9,000 members. I am here today to testify in the support of the National Institute of Deafness and Other Communication Disorders.

I would first like to thank Senator Harkin, chairman of this committee, for his tremendous efforts to provide critical funding to the new Institute in its early stages. Without his support the NIDCD would not have been able to achieve the early successes that it has. And Senator Inouye, I would like to take this opportunity to thank you for your efforts last year as chairman of the Defense Appropriation Subcommittee in assuring a thorough review of otolaryngology research in the military.

The NIDCD is a little more than 1 year old. In this short period of time there have been numerous program initiatives which are affecting the health and well being of children, adults and senior citizens of this country. We commend Dr. J. Moskowitz for his leadership during the first year of the NIDCD's operations. And we welcome Dr. James Snow, one of the Nation's leading otolaryngologists, head and neck surgeons as a first permanent director of the NIDCD.

The benefit to society of research in the area of deafness and other communication disorders will be substantial with advances in the areas of cochlear implants, restoration of voice after head and neck cancer surgery, location of the gene which causes deafness and blindness—so-called Usher's disease and many others.

In order to effectively pursue further research into these areas as well as explore new areas, the NIDCD requires a significant increase in funding. We are delighted that the advisory council of the NIDCD expects a 50-percent increase in grant applications at its next meeting in May. We must be able to fund worthwhile grant requests so as not to discourage young investigators.

The special panel on training has stated that there is an urgent need for new training of basic and clinical researchers in this area. The Institute has also sent out an announcement asking for proposals for regional research training centers.

The American Academy of Otolaryngology, Head and Neck Surgery request $165 million for fiscal year 1991 for the Institute, so that it may continue to fulfill its unique role in providing critical research.

On another note, Mr. Chairman, it has come to my attention that Senator Harkin asked the director of the National Cancer Institute, Dr. Sam Broder about the NCI's efforts in cancer prevention education. I would briefly like to tell you about the academy's through with chew campaign, which is informing young people about the dangers of smokeless tobacco, including the risk of developing cancer of the oral cavity.

I would like to present you with an educational packet, which has been distributed to all 20,200 secondary schools and 1,200 boys clubs nationwide. There is one packet for you and one that you might pass on to Senator Harkin.

PREPARED STATEMENT

Included in this packet is a videotape which features pitcher Nolan Ryan, American League president Dr. Bobby Brown, and it is narrated by Mel Allen. There is a lesson plan for teachers in the packet prepared by the National Cancer Institute and the academy. And our campaign, as I said, is dedicated to reducing the prevalence of cancer of the oral cavity among young Americans. And you might note in there the photos of Sean Marcy, the young Oklahoma athlete who used smokeless tobacco and developed the disease.

I thank you for this opportunity to testify before you. And I will be pleased to answer any questions you might have.

[The statement follows:]

STATEMENT OF JEROME C. GOLDSTEIN, M.D.

Mr. Natcher, members of the committee, ladies and gentlemen, I am Dr. Jerome C. Goldstein, M.D., Executive Vice President of the American Academy of Otolaryngology-Head and Neck Surgery, Inc., the largest organization of otolaryngologists-head and neck surgeons in the world with more than 9,200 members, including 96 percent of all board certified otolaryngologists.

The specialty of otolaryngology-head and neck surgery encompasses surgeons whose expertise involves the management of disorders of hearing, balance, the facial nerves, the nose, facial bones, as well as benign and malignant disorders of the mouth, trachea, larynx, thyroid and esophagus.

The National Institute on Deafness and Other Communication Disorders (NIDCD) has a unique role in the health of the American people. It provides the health initiatives for hearing, voice, speech, language, balance, taste and smell. Much of what it is concerned with affects the ability of men and women to communicate. Communication ties together the social and economic networks of our society. No longer do workers make their living only using physical strength. Today almost all Americans are involved in occupations which require communications, and most of the new jobs which are evolving and essential are nearly all based in the area of communication. Deficits in communication skills have been found to be the most important impediment to the youth of our cities in finding employment (see New York Times, Sunday, February 25, 1990).

NATIONAL INSTITUTE ON DEAFNESS AND OTHER COMMUNICATION DISORDERS (NIDCD)

The NIDCD is a little more than a year old. In this short period of time the Institute has more than fulfilled the expectations which the American people, the organizations both lay and professional who called for its establishment, as well, I am certain, of the Members of Congress who created it, have had for this endeavor. There have been numerous program initiatives which are affecting and will affect the health and well being of children, adults and senior citizens of this country. The NIDCD has been fortunate in having excellent leadership during its beginning year. We would like to acknowledge publicly the superb leadership of Dr. Jay Moskowitz, who was the first Acting Director of the NIDCD. The program of the NIDCD is so appealing and important that the NIH has been able to attract one of the nation's leading otolaryngologists, Dr. James Snow, Jr., to become the first Director of the NIDCD.

The NIDCD has attracted excellent science to be carried out in the area of communication disorders. There will be approximately a 50-percent increase in the number of new grants considered at the next Advisory Council meeting in May 1990. It is perceived that the growth of this institute, which serves a fundamental scientific mission, has just begun. It is clear that a massive opportunity awaits us, and that the scientific community is anxious to begin work—a large number of these excellent scientific proposals must be funded.

The task force report of January 1989 and the special panel on training, which met in July 1989 (the latter in response to your committee report, pages 81 and 154 of last year), both clearly stated that there is the urgent need for the training of basic and clinical research in the area of deafness and communication disorders.

Also, the institute has sent out an announcement for proposals for research and training centers. There has been an extremely large response for this announcement, as this area of biomedical science now has the leadership and structure so that it may make its uniquely central societal contribution. It is necessary to establish a number of these centers through the United States; they will require additional funding.

There are other areas of increased scientific activity which have emerged during the last year. These include further development of the intramural program in basic molecular biology and genetics. The program in the NIH Clinical Center is being developed to carry out clinical investigation, to serve the needs of other units in the Clinical Center, and become a training ground to develop clinical researchers in the area of deafness and communication disorders. These programs will require resources so that they can be properly organized and stabilized.

The benefit to society of the development of the basic and clinical science in the area of deafness and other communication disorders will be substantial. There are many examples which can be given, such as cochlear implants, restoration of voice, location of the gene which causes deafness and blindness (Usher's Disease), and many others.

I would like to comment upon another advance which has come about from the support of the NIH and the NIDCD.

Last year, Mr. Chairman, you asked many witnesses, "Please tell me about NIH-supported research advances which have improved the health of the American people." Let me provide an excellent example.

Up until a few years ago we were not able to obtain accurate behavioral hearing tests in infants and toddlers. It is critical that there be an accurate and precise measure of an infant's and toddler's hearing so that a correct diagnosis of the hearing impairment can be made. After the diagnosis is made, there may be the need for a type of intervention, be it an operation, a hearing aid, language therapy, or another form. All of these interventions require the precise knowledge of the hearing of the infant or toddler. NIH-supported research has now resulted in the ability to accurately and precisely carry out behavioral tests in each ear, at each frequency, routinely in an infant as young as five (5) months of age, at a low cost. This is the technique of Visually Reinforced Audiometry (VRA). This NIH-developed technique is now being disseminated throughout the world. This advance is critically important for it is the infant who needs the best hearing if he or she is going to master language and become an emotionally adjusted and productive person in our society.

Consequently, we can now diagnose many types of hearing losses at five months of age, which we could not do previously until the child was four or five years of age, a delay in diagnosis that resulted in lifetime crippling communication disorders. We can now effectively intervene and help that child overcome his or her handicap because of NIDCD-supported research.

SUMMARY AND RECOMMENDATIONS

The opportunities indicated above need funding, now.

The American Academy of Otolaryngology-Head and Neck Surgery requests $165 million for fiscal year 1991 for the institute, so that the NIDCD may continue to fulfill its unique role in providing for the research which affects the basic communication abilities of a society which is dependent upon communication for its social and economic well being. Research and the resultant progress in the area of communication disorders is a most valuable investment in the future of this nation as a world leader and as a just and prosperous society.

Senator INOUYE. Thank you.

Are we having any success in convincing baseball players to do away with chewing tobacco?

Dr. GOLDSTEIN. I think we are. We have worked closely, for example, with Dr. Bobby Brown and, he is a physician himself of course, and very interested in this problem. And we have a lot of them switching to bubble gum. Bobby Brown and Nolan Ryan cochair the Athletes Through with Chew. And they are trying to impress ballplayers with the fact that they are a role model for our Nation's youth.

Senator INOUYE. Are you satisfied with the progress made by NIDCD?

Dr. GOLDSTEIN. Oh, we are very excited about that. And just the fact that they are stimulating so many young researchers. And the growth and applications of about 50 percent is a very exciting thing.

Senator INOUYE. We will try to keep up that enthusiasm.

Dr. GOLDSTEIN. Now we have to fund them. Thank you.

Senator INOUYE. We will do our best, sir, thank you.

STATEMENT OF NORVAL W. KING, M.D., ASSOCIATE DIRECTOR FOR RESEARCH, NEW ENGLAND REGIONAL PRIMATE RESEARCH CENTER

Senator INOUYE. The next witness is the associate director for research, New England Regional Primate Research Center, Dr. Norval W. King. Thank you for your patience.

Dr. KING. Thank you very much, Mr. Chairman.

I am Dr. Norval King. I am an associate professor of pathology at the Harvard Medical School and also, as you mentioned, director of research at the New England Primate Center.

I want to thank the committee for the opportunity to appear before it today. I am here representing all seven of the NIH-sponsored regional primate research centers. I wish to bring to this committee's attention several circumstances that now seriously undermine the ability of these centers to effectively carry out their mandated missions and to offer two recommendations as to how the Congress could restore the overall effectiveness of these vital resources.

The regional primate research centers were established by the U.S. Congress in 1960 as a national resource to support research directed toward a solution of the Nation's major health problems. These centers have made numerous contributions in the areas of cardiovascular disease, cancer, inflammatory bowel disease, neurological disorders such as Parkinsonism and Alzheimer's disease, and more recently cocaine addiction and AIDS.

Over the last decade there has been a marked reduction in the number of nonhuman primate research facilities at academic and other research institutions in the United States because of laws prohibiting the importation of certain primates, the escalating price of colony born animals and the increase of cost caging equipment, space, and personnel required to comply with more stringent Federal laws and regulations.

Scientists at these institutions are increasingly turning to the regional primate centers as sites to conduct their research. This is straining our already heavily committed resources.

Primate centers have had to develop their own breeding colonies to ensure a continuous supply of animals for research. This was not anticipated in the original construction of these centers and, thus has taxed their limited infrastructure. The primate centers have also been a victim—in a sense—of their own successes.

Shortly after the first description of AIDS the primate centers identified a disease of monkeys that is very similar to AIDS. It is now recognized as the best animal model for AIDS research, especially for vaccine trials and for new forms of therapy. As a matter of fact, the first successful vaccine trials using this animal model were done at my center and at the center in Louisiana just recently.

As part of the national effort the primate centers have made extraordinary commitments of their resources including animals, biocontainment space, laboratory facilities, equipment, and personnel to AIDS-related research. However, this has been at the expense of other ongoing programs of equal, if less urgent, importance.

Yet each of the last 3 years the base grant awards to the regional primate research centers have been cut. I have documented that in a table which you will find in my written testimony.

The base grant is the very heart of the primate centers program, in that it is the primary source of funds to recruit new scientists and support staff, support these badly needed breeding colonies, which I have already alluded to, and to develop primate models and pay the ever-increasing cost of operation, including heat, light, and maintenance.

Of immediate concern is the administration's fiscal year 1991 budget which calls for level funding for the primate research centers. For this reason, I hasten to point out that the recommended and approved funding level of the NIH National Research Resources Council for the Primate Research Centers Program is in excess of $35 million.

Current funding, however, for these seven centers is $25.5 million or $9.7 million less than the council recommended budget for this program.

Finally, legislation passed by the 90th Congress requiring that the biomedical community using primates in research provide for the psychological well being of these animals will undoubtedly require expenditures of large sums of money that the centers simply do not have, in order to expand and upgrade their facilities.

In conclusion, Mr. Chairman, I ask the committee to critically examine and consider two major courses of action that would resolve these problems. One, review the appropriation for the primate center's program and make every effort to approach the $35 million recommended and approved by the NIH's National Research Resources Council.

PREPARED STATEMENT

Two, initiate a 5-year program with congressional authorization for construction without requirement for matching funds at a level of $10 million per year to construct housing and breeding facilities for animals to enable the seven centers to comply with the congressional legislation calling for such improvements.

I thank you, Mr. Chairman, and would entertain any questions that you might have.

[The statement follows:]

STATEMENT OF NORVAL W. KING

Chairman Harkin and Members of the Committee:

I am Dr. Norval W. King, Associate Professor of Comparative Pathology and Associate Director of the New England Regional Primate Research Center at the Harvard Medical School. I am here today representing all seven of the NIH-sponsored Regional Primate Research Centers, each located at a distinguished University in California, Georgia, Louisiana, Massachusetts, Oregon, Washington and Wisconsin.

I first want to thank the Committee for the opportunity to appear before you to alert you to several events and circumstances that seriously threaten the ability of the seven Centers to carry out their mandated missions.

The Regional Primate Research Centers were established by the United States Congress in 1960 as a unique national resource designed to meet a crucial need of the biomedical research community for specialized facilities, equipment and trained personnel to house, breed and maintain nonhuman primates for research efforts directed towards solving this country's major health problems. These Centers were purposely located within defined geographic regions of the country, so as to be generally accessible to all scientists requiring such a resource. Moreover, the concept of creating regional Centers for specialized research involving the use of nonhuman primates was also more cost-effective than creating numerous, small primate research colonies designed to support the many individual, federally-funded research grants requiring such species. Between 1960 and 1962, Congress made funds available to universities, on a competitive basis, for the construction and operation of these unique Centers. All seven Centers were completed and fully operational by 1965. Now, thirty years later, the Centers continue to be supported by competitive core grants awarded by the National Center for Research Resources, formerly known as the Division of Research Resources, and by individual awards to investigators from the categorical institutes of NIH.

Over the last 30 years, the Regional Primate Research Centers, and the many talented scientists affiliated with them, have made numerous contributions to the understanding of some of the most important enduring as well as newly emerging health problems confronting humankind. These include: cardiovascular disease, cancer, inflammatory bowel disease, debilitating neurological diseases such as Parkinsonism and Alzheimer's disease, and more recently, drug addiction and AIDS, all of which are major health problems here in the United States. In addition, research using nonhuman primates at these Centers has also contributed substantially to the progress made in the development of methods that hopefully will lead to the effective control of such devastating diseases as malaria and leprosy which represent serious global health problems. Thus, the Regional Primate Research Centers are clearly fulfilling their mandated mission of effectively contributing to the improvement of the health of the nation as well as the world.

Despite the many scientific contributions of the Regional Primate Centers Program to a wide variety of health related issues, there have been a number of recent developments that seriously threaten the ability of these Centers to maintain the diversity of research programs that have been their strength in the past. I will briefly mention each of them for the Committee's benefit, and will conclude with a several suggestions made by the Primate Center Directors as to how the Congress could remedy this increasingly serious problem.

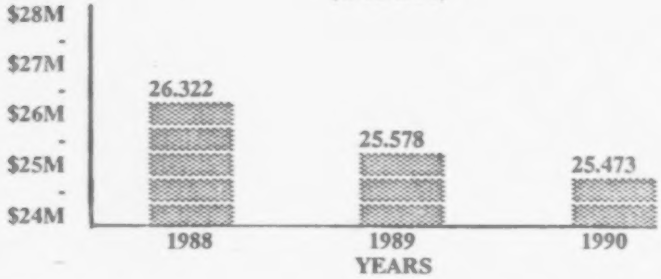
Over the last decade there has been a drastic reduction in the number of nonhuman primate facilities at academic institutions, research laboratories and the pharmaceutical and biotechnology industries in the United States. The reasons for this are manifold, and include: laws prohibiting the importation of certain primate species from their natural habitats, increased cost of colony-born primates from commercial suppliers, implementation of higher standards for care and housing of primates resulting in increased costs for new caging, equipment, space and personnel to comply with new federal laws and regulations. Accordingly, these institutions and their researchers are increasingly turning to the Regional Primate Research Centers as sites to conduct their investigations. This trend, although welcomed, has placed considerable demands on the already heavily committed resources of the Centers.

Because most nonhuman primates used in research are no longer taken from their natural habitats, the Regional Primate Centers have had to develop their own breeding colonies to ensure a continuous supply of animals for research. The need to maintain large breeding colonies, not anticipated in the original design and construction of these Centers, has also taxed the Centers' resources.

Ironically, the Primate Centers have also, in a sense, been a victim of their own success. Shortly after the first description of human AIDS, my colleagues and I at the New England Primate Research Center, and researchers at the California Primate Research Center described a naturally occurring disease of macaque monkeys that was remarkably similar to this new human epidemic. Soon thereafter a virus closely related to the human AIDS virus was isolated from monkeys dying of this disease. This virus is now referred to as the simian immunodeficiency virus or SIV. Because it induces a fatal disease in rhesus monkeys that is almost identical to human AIDS - unlike HIV infection in chimpanzees which does not - the SIV-rhesus monkey model is now recognized as the best animal model system for studies of mechanisms involved in disease induction, vaccine trials and new forms of therapy for this disease. This has been repeatedly emphasized in both issues of the National Academy Sciences publication "Confronting AIDS". The first successful vaccine trials using the SIV model have been recently described by investigators at my own Center and those at the Delta Center providing the first conclusive evidence that an AIDS vaccine is indeed possible. I am convinced that if the NIH-funded Primate Research Center Program had not existed, this naturally occurring animal model of AIDS would not have been recognized or available to researchers today. As part of the national AIDS research effort, the Regional Primate Centers have made extraordinary commitments of their resources, including animals, biocontainment space, laboratory facilities, equipment and personnel to studies to combat this disease. However, this has been at the expense of other ongoing programs of equal, if less urgent, importance.

Another example of the success of the Primate Center program is the recent advance in our understanding of brain mechanisms responsible for cocaine addiction. In just the last few years, researchers at the New England Regional Primate Research Center have identified specific receptors for cocaine in the brains of monkeys and have begun to map the distribution of these receptors in the brain and other organs. Coordinated research using a highly predictive model of experimental drug abuse in monkeys has provided compelling evidence that brain cocaine receptors are principal targets underlying the psychopharmacological effects and abuse liability of cocaine. Research of this type constitutes one of the most promising leads we have for understanding neural processes involved in addiction and for developing rational approaches to drug therapy.

For each of the last 3 years, the base grant awards to the Regional Primate Centers have been cut (See Table Below).



DECLINE IN CORE SUPPORT FOR REGIONAL PRIMATE CENTERS

(1988-1990)

Funds for core support have decreased in absolute dollars for past 3 years

These awards support the basic operating costs of the Centers and their cuts have substantially impacted the ability of the Centers to keep pace with the increasing demand for animals, facilities, space and services required by outside investigators desiring to utilize the Centers for their research and by the additional staff hired as part of the expanded AIDS research program. The base grant is the very heart of the Centers Program in that it is the primary source of funds to recruit and employ well-qualified scientists and support staff, support of breeding colonies, development of new and improved primate models, and pay the necessary and ever-increasing costs to operate a facility including heat, light and maintenance. Of particular concern is the Administration's FY91 budget which calls for a flat funding level for the Regional Primate Centers Research Program. This will result in 4 years of no financial growth for the program. I wish to point out, indeed emphasize, that the approved funding level for the Primate Centers Program as determined by peer review/study section/council mechanisms of N.I.H. is in excess of $35 million. The FY 90 funding is $25,473,00, or 9.7 million dollars less than the N.I.H. National Research Resources Council recommended budget for this Program.

Finally, the 90th Congress passed legislation requiring that the biomedical community provide for the psychological well-being of nonhuman primates. While, the final regulations from the United States Department of Agriculture on this issue have not yet been fully formulated, it is clear that they will require substantial expenditures of money which the Primate Centers simply do not have. These requirements, coupled with the lack of construction authority and enabling funds since the initial establishment of the Centers over 30 years ago, now poses a serious infrastructure problem in providing a quality environment for the ever-expanding biomedical research community. We urge the Congress to initiate a five-year appropriations plan to meet these new regulations by providing 10 million dollars per year to improve and upgrade animal facilities at the seven Centers. This appropriation should also contain the provision for construction authority without matching funding.

In conclusion, I ask the Committee to critically examine and consider two major requests that would provide funding for our nation's unparalleled Primate Research Center Program at a level commensurate with its international reputation for scientific achievements and service as a unique resource to the widely diverse biomedical community.

ONE: Review the appropriation for the Primate Centers Program and make every effort to approach the N.I.H. National Research Resources Council recommended and approved level of $35 million.

TWO: Initiate a five-year program with Congressional authorization for construction without requirement for matching funds at a level of 10 million dollars per year to construct housing and breeding facilities for animals, to enable these Centers to meet the spirit of the Congressional legislation calling for such improved facilities.

The Directors of the seven Regional Primate Research Centers very much hope that the members of the Senate Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies will take our request under serious consideration in the interest of solving many of our nation's health problems.

Senator **Inouye**. Last year the committee strongly recommended the development of alternative methods—research models that did not call for the use of animals. Are we making any progress there?

Dr. **King**. There are several centers around the country who receive funding specifically for that purpose. I think there is some progress made, particularly in the area of drug testing, particularly the Drays test which you may have heard about. I am aware of several new methods that are being used to get rid of that particular test.

In terms of alternatives to diseases like AIDS, I do not think one is going to ever be able to do that in a test tube. The immune system is far too complex. There are too many factors involved, too many different kinds of cells that have to interact one with another for normal immune functions that one will never be able to mimic that in a test tube or to really get a handle on the basic mechanisms involved in disease induction.

Senator **Inouye**. Now under the present state of the art, in order to cope with these exotic diseases you must conduct research using primates?

Dr. **King**. In terms of AIDS research, I think, as I have already alluded to, the National Academy of Science has repeatedly indicated that the nonhuman primate model and its related SIV or simian immunodeficiency virus, is by far the best model we have for human AIDS today.

As you know, the chimpanzee is in fact susceptible to the human AIDS virus. But depending on how you look at it, fortunately or unfortunately, they do not get sick. So as an animal model in terms of understanding how the human AIDS virus actually causes disease, the chimpanzee is not very useful.

On the other hand the chimpanzee in limited numbers—and I emphasize that limited numbers—will become very important once there is an HIV vaccine about to be ready to go into man.

We at our center have not worked with HIV. We are working with the simian immunodeficiency virus. People at our center and at the Delta Center in Louisiana have shown now for the first time conclusively that it will be possible to make a vaccine against human AIDS. That is something that was still in doubt up until very recently. And I think that is some progress.

Senator **Inouye**. I thank you very much, sir.

Dr. **King**. My pleasure.

STATEMENT OF R. BARRY SLEIGHT, REPRESENTATIVE, CHRONIC SYNDROME INFORMATION INSTITUTE

Senator **Inouye**. Our next witness represents the Chronic Fatigue Syndrome Information Institute, Mr. R. Barry Sleight.

Mr. **Sleight**. I present this testimony as an individual patient with chronic fatigue syndrome and also on behalf of 400 patient support groups covering every State and national organization involved in this disease, which has also been known by other names such as chronic Epstein-Barr virus syndrome and chronic fatigue immune dysfunction syndrome.

The 1989 bill was accompanied by a report with related language including funding the CDC for a small surveillance activity on this disease. And we want to thank the committee and its staff for leadership in the Federal response.

There has been increasing public health and legislative attention focused on this disease; 26 States have declared a commemorative CFS day, week, or month. The largest related medical conference in San Francisco last April was conducted by public health officials and had a stated purpose to include whether CFS is connected to AIDS.

A CDC document related to this conference called CFS an emerging epidemic. And there has been legislation, public health initiatives in Nevada, Minnesota, and California. Last month the National Governors Association passed a resolution calling on the Congress to increase the coordination of CFS research in programs within the public health community for the exchange of information about this disease. And that is only the second time that they have ever passed a resolution on a specific disease.

The small CDC program has been running since October. A number of planned related CDC activities are not underway because of lack of funding within the division of viral disease at CDC.

The CDC program is based on a working case definition, including many symptoms that are involved in this disease, such as fever, sore throat, swollen and painful lymph nodes, muscle weakness and aches, and others. There are over 20 other symptoms in the medical literature for this disease.

The NIAID has a small intramural program involving this disease that currently funds only three extramural research grants directly related.

There have been apparent higher rates of cancers including deaths documented in this disease as well as eye, muscle, heart, blood, liver, breathing, brain, neurological, cognitive, and endocrine abnormalities documented. And research continues to show that this is a document that involves the immune system.

The Epstein-Barr virus had been proposed as a cause of the disease at one time, but the NIAID director has reported to the Congress that the connection of this virus is weak at best. He similarly has reported that it seems likely that CFS is triggered by an infectious agent, probably a virus which grows in lymphoid tissue and results in immune dysfunction. The CDC director similarly reported that CFS involves immunologic abnormalities such as specific antibody or natural killer cell deficiencies.

Evidence of retroviral genetic material and retroviral replications similar in type to that found with the AIDS virus has been found in some patients with CFS. The summary of current biomedical research is that at least some cases of CFS represent a series acquired immune dysfunction disorder.

Most patients, sir, are bedridden, unable to work full time, lack health insurance. Many have problems trying to obtain Social Security disability benefits.

Several published and unpublished estimates suggest that as many as 1.5 percent of the populous may be falling victim to this disease. We are thankful for the Federal response to the CFS so far, but we feel it should be dramatically increased to meet the challenge posed. And we are especially concerned that the activities of the NIH and the CDC continue to be less than is consistent with a new epidemic of a disease of the immune system.

And we offer several suggestions to the Congress to improve Federal activities related, including: to increase and better coordinate research in the CFS the NIH should be funded to establish a multicenter research consortium including the centralized reference laboratory and data center. This will build on a great deal of existing research that has been completed by the private sector. That would be $822,000.

PREPARED STATEMENT

They should be funded to conduct a CFS research conference that is already in planning at $300,000, and they should expand extramural activities including internationally. To continue their planned epidemiology and related activities the CDC should be funded above current levels to expand their surveillance activities and also to fund it with $600,000 additional for related studies that have been planned since fiscal year 1987.

And to improve responsiveness to disabled CFS patients, the Social Security Administration should be directed to update its guidelines for disability evaluation on this disease.

I thank you for the opportunity to speak today.

[The statement follows:]

STATEMENT OF R. BARRY SLEIGHT

Mr. Chairman, I present this testimony as an individual patient with Chronic Fatigue Syndrome, or CFS, and also on behalf of over 400 patient support groups and national organizations involved in matters related to this disease. This disease has also been known by other names, including Chronic Epstein-Barr Virus Syndrome and Chronic Fatigue Immune Dysfunction Syndrome.

The 1989 Labor-HHS-Education Appropriations Bill was accompanied by report number 100-127, which contained related language. The National Institutes of Health was urged to expand research on this disease, the Social Security Administration urged to review CFS disability issues, and the Centers for Disease Control funded to expand a small surveillance research activity on this disease. Our thanks to this Committee, and its able staff, for leadership in the Federal response to this disease.

During the past year there has been increasing public health and legislative attention focused on this disease; 26 States have declared a commemorative CFS day, week, or month. The largest related medical conference ever was conducted by public health officials in San Francisco last April; one of the stated Conference purposes was to explore whether "CFS is connected to AIDS." A CDC document related to this Conference called CFS an "emerging epidemic." Legislation regarding this disease has passed the Nevada legislature, and public health initiatives on CFS have been undertaken in Minnesota and California. One month ago, the National Governor's Association passed a resolution calling on the Congress and the White House "to increase the coordination of Chronic Fatigue Syndrome research and programs within the public health community for the exchange of information about this disease."

The small CDC surveillance program has been recruiting patients since October. A number of other planned, related CDC activities are not underway due to lack of funding within the CDC Division of Viral Diseases.

The CDC program is based upon a research Working Case Definition including many symptoms that our patient population suffers with, such as fever, sore throat, swollen and painful lymph nodes, muscle weakness and aches, joint pain, sensitivity to light, spots in the field of vision, fatigue after exercise, headaches, mental confusion, and sleep disturbances. This definition is intentionally narrow for research purposes, and it is important to note that there are over twenty other symptoms listed in the medical literature for this disease.

The National Institute of Allergy and Infectious Diseases has a small intramural program involving CFS, but currently funds only three extramural research grants directly related to CFS.

The larger research community has been providing increasing information related to CFS and is increasingly focusing on serious untoward outcomes.

Apparent higher rates of cancers, including deaths, have been documented. Eye, muscle, heart, blood, liver, breathing, brain, neurological, cognitive, and endocrine abnormalities have been documented in CFS patients. Some of these irregularities are very similar to those found in patients with multiple sclerosis or AIDS.

Research continues to show that CFS is a disease which involves the immune system. A number of medical articles have reported a variety of immunologic irregularities and associated metabolic defects in CFS patients. Irregularities, some of them profound, have been found in many key immune system components.

Since the early 1980's, a number of infectious agents, as well as some genetic predisposition, have been proposed by researchers as involved in some way in CFS, including enteroviruses and the Epstein-Barr virus, though the NIAID Director has reported to the Congress that the connection to this latter virus is "weak at best". A number of agents, in a genetically predisposed individual, may be able to trigger the disease.

The director of the NIAID has reported to the Congress that "it seems likely that CFS is triggered by an infectious agent, probably a virus, which grows in lymphoid tissue and results in immune dysfunction" and that "immunological abnormalities can be the direct result of viral destruction of lymphoid cells, with the result dependent upon the subset of cells preferentially infected by the virus and the immunogenetic constitution of the infected individual." The CDC Director has similarly reported that CFS involves "immunologic abnormalities, such as specific antibody or natural killer cell deficiencies." Evidence of retroviral genetic material and retroviral replication, similar in type to that found with the AIDS virus, has been found in some patients with CFS. The summary of current biomedical research is that at least some cases of CFS represent a serious acquired immune dysfunction disorder.

Most CFS patients are unable to work full time, and many are bedridden. Many lack health insurance. Patients continue to encounter a variety of difficulties in obtaining approval for Social Security disability benefits.

There is still no government data on incidence of Chronic Fatigue Syndrome, but several medical journal articles and numerous reports in the popular media suggest that this disease has been concentrated in certain geographic areas around the country, that certain groups have a higher incidence, and that CFS has increased in incidence dramatically since the early 1970's. Several published and unpublished estimates suggest that as many as one-and-one-half percent of the populace may be falling victim to this disease.

The Federal response to Chronic Fatigue Syndrome has been most welcome, but should be dramatically increased to meet the challenge posed by the serious nature of this disease.

We are concerned that the activities of the NIH and the CDC regarding CFS continue to be less than is consistent with a new epidemic of a disease of the immune system.

We offer suggestions to the Congress to improve Federal activities related to Chronic Fatigue Syndrome, as follows:

To increase and better coordinate research into CFS, the National Institutes of Health should be funded to establish a multicenter research consortium including a centralized reference laboratory and data center ($822,000); should be funded to conduct a CFS research conference ($300,000); should be directed to designate a senior official to coordinate NIH activities concerning CFS; and should expand its extramural activities, including internationally.

To continue planned epidemiology and related activities, the CDC should be funded above current levels to conduct case-control, immunologic, virologic, rheumatologic, genetic, toxic, and long-term follow-up studies ($600,000 additional).

To improve responsiveness to disabled CFS patients, the Social Security Administration should be directed to update its guidelines for disability evaluation of CFS.

Senator INOUYE. You have testified that most CFS patients are either bedridden or find it very difficult to work. You are a patient also, are you not?

Mr. SLEIGHT. Yes, sir.

Senator INOUYE. Why are you so fortunate that you can work?

Mr. **Sleight**. Well, I am at the lucky end of the spectrum. I do not work full time at anything, Senator. I do this as a volunteer activity, and I am unfortunately forced to fall back on family resources in order to get by.

There is a spectrum of disease, and the ones that are of most concern from a public health standpoint and I think, therefore, from a public policy standpoint are the worst patients who this large group that is bedridden frequently for months at a time, in many cases, seemingly for an interminable period of time.

And these people live a very limited lifestyle. They get up and go to the bathroom a couple of times a day, stagger to the kitchen. And this is what their life is like.

It, of course, impacts on all your public service programs. They are not paying taxes in, they are taking public services out. And as the numbers increase, there has been an apparent increase in numbers since the 1970's of this disease. The problem gets worse.

Senator **Inouye**. What is the present approximate number of CFS patients?

Mr. **Sleight**. There are several estimates that range as high as 1.5 percent of the populous. There was a prospective study done in Germany that is probably the scientifically best such study done, and it was in that range.

Senator **Inouye**. So it is over 3 million?

Mr. **Sleight**. It could well be over 3 million. We will not have any hard data in the United States unless and until the CDC get further along on their surveillance and related epidemiology activities. And we encourage funding for them to do exactly that.

Senator **Inouye**. I will do my best, sir.

Mr. **Sleight**. Thank you, sir.

STATEMENT OF CHARLENE WALDMAN, EXECUTIVE DIRECTOR, PAGET'S DISEASE FOUNDATION, INC.

Senator **Inouye**. And our final witness this afternoon is the executive director of the Paget's Disease Foundation, Inc., Ms. Charlene Waldman.

It has been a long week.

Ms. **Waldman**. Thank you.

First of all I would like to request that our entire statement be placed into the record, and I am going to speak a little more informally. And I am sure that all of you have heard some of the things that I am going to say before. But I want to start off by saying, as my colleagues have said very eloquently here today, that we are here to advocate for $50 million over and above the President's recommended budget for our Institute, which is the Arthritis Institute. And our disease, Paget's disease of bone is one of those diseases that is served by the Institute.

So, rather than repeating some of the same statistics that you have heard before today by Arlene Pessar and Leigh Callahan of the Arthritis Foundation and others, let me say that we—and that is the Paget's Disease Foundation, the voluntary agency for patients with Paget's disease of bone and the American Society for Bone and Mineral Research, who I also represent today, which is the medical professional organization of researchers and physicians who deal with bone disease—strongly urge that adequate funding be allocated for NIAMS, so that all of the diseases that you heard about today and the bone diseases, which I will talk about briefly, can receive the research attention that they desperately need.

I want to read you just two or three sentences from a typical letter from a Paget's disease patient. This letter was received in our office this week.

> Dear Sirs, my husband has had Paget's disease for about 20 years, first in his hip, then in his knee and now in his right foot. He has not been able to work for 7 months. Also the hearing in one of his ears is affected. No doctor knows what to do for him. He suffers a lot and no one knows what causes it.

That, unfortunately, is a typical letter that we receive every day of the year from patients all over the United States and all over the world as well.

Paget's disease and osteoporosis and other bone diseases are the leading cause of disability in the United States. And that is a very, very important fact. Also both Paget's disease as well as osteoporosis are becoming increasingly prevalent in the elderly, which is the most rapidly growing segment of our society.

To briefly explain what Paget's disease is—hopefully many of you in the room do know what it is, but most of the general public does not. It is the second most prevalent bone disease after osteoporosis. It is a chronic condition that is characterized by excessive resorption or breakdown of bone and increased formation of new bone.

This disease is rare in people under 40 but occurs in 1 percent to 3 percent of those over 65 and 10 percent of those over 80. So it is a very serious chronic and often debilitating disease of the elderly.

The abnormal increase in bone remodeling in Paget's disease results in bone that is dense but fragile and may lead to very striking skeletal deformities, such as a markedly enlarged skull and bowing of the legs. In very severe cases Paget's disease can cause loss of hearing, as the lady who wrote that letter said, neurological problems and very severe pain and crippling.

The cause of Paget's disease is unknown. Not nearly enough research has been done to determine the cause. Recent studies indicate that the disease may be caused by a slow virus, which is a virus that is dormant for many years before any symptoms appear.

This research needs great support so that an answer can be found for the cause of this disease. Researchers are very, very interested in Paget's disease research, because if an answer or answers are found for the phenomena which causes bone to overgrow in the elderly, when usually elderly people have a decrease in bone mass, if answers are found for this it will not only help Paget's disease but will also provide important information in the management of osteoporosis and other bone diseases.

Considerable research in the bone field is funded by NIAMS as I mentioned before. And as you have heard our colleagues say today, the budget of our Institute is underfunded, it has grown only 2 percent annually in constant dollars; it has the lowest pay line of any Institute in the NIH.

For those patients who suffer from Paget's disease and these other bone diseases, this is very, very discouraging news. Also, many of the talented researchers in this country are reluctant to pursue bone disease research, because they know of the funding problems with our Institute.

For these reasons we encourage the $50 million that has been recommended over the President's budget for fiscal year 1991. If these dollars are not allocated, the terrible pain and disability as well as the economic cost related to these bone diseases will not be lessened.

Both the Paget's Disease Foundation and the American Society for Bone and Mineral Research are very, very grateful for the many opportunities that have been and continue to be provided by the research and educational programs of NIAMS and particularly the role of the Congress in providing the means for these programs.

In the past year just specifically NIAMS through its clearing house compiled the first ever comprehensive bibliography on Paget's disease that has been published in the United States or elsewhere. We are very grateful for this joint effort and also, we appreciate the support of our Institute in a treatment symposium that we held in New York City in October and in many other educational programs and activities.

PREPARED STATEMENT

In closing, again, we thank you for allowing me to speak both on behalf of the Paget's Disease Foundation, the American Society for Bone and Mineral Research, but most importantly on behalf of the millions of people who suffer from these debilitating diseases and hope that funding will be allocated, so that the necessary research in other programs can be implemented for these bone diseases.

Thank you. I would be glad to answer any questions.

[The statement follows:]

STATEMENT OF CHARLENE WALDMAN

The Paget's Disease Foundation is pleased once again to have the opportunity to appear before the subcommittee. Today, we speak on behalf of the Paget's Disease Foundation and American Society for Bone and Mineral Research for the estimated 27,000,000 Americans, both young and old, who suffer from Paget's disease, osteoporosis, and related bone disorders. Musculoskeletal diseases are the leading cause of disability in the USA. Both Paget's disease as well as osteoporosis are becoming increasingly prevalent in the elderly, the most rapidly growing segment of our society.

Paget's disease of bone, the second most prevalent bone disease after osteoporosis, is a chronic disease that is characterized by excessive resorption or breakdown of bone and increased formation of bone. The disease is rare in people under the age of 40 but occurs in 1 to 3 percent of persons over age 65 and 10 percent of those over 80.

The abnormal increase in bone remodeling results in bone that is dense but fragile and may lead to striking skeletal deformities such as a markedly enlarged skull and bowing of the legs. In severe cases, Paget's disease can cause loss of hearing, neurological problems, severe pain and crippling.

The cause of Paget's disease is unknown. Recent studies indicate that the disease may be caused by a "slow virus", a virus that lies dormant for many years before symptoms appear. The virus appears to invade the bone cells that cause resorption or breakdown, activates them and causes them to markedly proliferate.

There is much interest in the factors that cause local bone remodeling in normal and disease states including growth factors, hormones and cytokines. Understanding how and why skeletal remodeling takes place and why it is greatly enhanced in Paget's disease would provide important new information that could shed light on other bone diseases including osteoporosis.

Considerable research in the bone and mineral field is funded by the National Institute of Musculoskeletal and Skin Diseases. However, research programs in that institute are under severe constraints because of inadequate funding. Since its inception in 1987, the budget of NIAMS has grown only 2 percent annually in constant dollars. The institute can fund only some 15 percent of approved grants, and the payline continues to be the lowest of any of the institutes of the National Institutes of Health. For those individuals who suffer from bone, joint and skin disorders, this is not good news. The lack of adequate resources is discouraging talented young investigators from considering careers in research devoted to discovering the causes, treatment and prevention of musculoskeletal, joint and skin diseases.

Because of the inadequate funding of NIAMS and to begin to achieve parity with the other institutes, we strongly endorse the proposal to increase funding for the institute by $50 million over the president's recommended budget to $226,000,000 beginning in fiscal year 1991. Without adequate dollars for research, the pain and disability as well as the economic cost related to musculoskeletal diseases will not be lessened.

If we as a nation do not take care of the health needs of our population now, the problem will worsen because of the increasing aged in our society. Adequate commitment to medical research now will reduce the costs of health care in the future.

Both the Paget's Disease Foundation and the American Society for Bone and Mineral Research appreciate the many opportunities that have been and continue to be provided by the research and educational programs of NIAMS and particularly the role of the Congress in providing the means for these programs. We also acknowledge the assistance of NIAMS in providing workshops and conferences to disseminate information about the pathogenesis, epidemiology and treatment of bone disease.

In closing, we again want to thank you for allowing us to speak on behalf of the many patients who suffer from Paget's disease, osteoporosis and other bone diseases that are so prevalent in our country.

Senator **Inouye**. I thank you very much, Ms. Waldman.

May I advise those who have testified in favor of the $50 million for NIAMS have somehow found their target. Because all of you have suggested that the years beyond 65 may be rocky if research programs are not carried out. And I do not want to end up my life with Paget's or arthritis or anything like that. So I will personally see to it that you get your $50 million.

Ms. **Waldman**. Thank you so much.

SUBCOMMITTEE RECESS

Senator **Inouye**. Thank you very much. The subcommittee will stand in recess until 9:30 a.m., Thursday, March 29, when we will meet in SD-116 to continue our public witness hearings on the budget request.

[Whereupon, at 1:40 p.m., Wednesday, March 28, the subcommittee was recessed, to reconvene at 9:30 a.m., Thursday, March 29.]

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